Dear Caregivers,

You are most likely receiving this information because your child has been or may be referred for an Autism evaluation, or has recently received an Autism diagnosis. Learning this information can be overwhelming for many, especially when so much of what you hear and see about Autism is presented in a negative and scary way. Most people only know about Autism by stereotypes like "avoids eye contact," "does not interact with others," "lines up toys," "is not able to speak or communicate," "does not point," etc - or to the other end of the spectrum- "is a genius," or "has savant skills." The truth is, most people diagnosed with Autism fall in the middle of those extremes: many do make eye contact, many have friends, they can be creative, they can point and share interests, and often are just not as different as most people seem to think.

Autism is a constellation of characteristics with differences seen in language, socialization, and repetitive thoughts/actions, but these differences are not always easy to spot, and as a result many adults and children go undiagnosed or misdiagnosed. Because the vast majority of people understand Autism only in extremes and because the majority of information available about Autism is painted in a negative light, a stigma is attached to the diagnosis and caregivers are often afraid when it is brought up. But the truth is, Autism is not wrong or bad. Autism is simply a difference in the brain. It can impact people in a variety of ways, some more significantly than others. But Autism does NOT mean a child will not be happy, will not speak or communicate, will not have a job, or will not have a family. It may take time, but talking about and viewing Autism in a more positive way can be helpful to better understand a child, accept a child for who they are, support and advocate for a child, and most importantly help a child better understand themselves.

Attached to this letter, you will find quite a bit of information that may be overwhelming to some. It's recommended that each person go through the information in a way that's best for them. For some that may mean reading everything in one sitting, while others may need to go through a little bit at a time. However you want to do it is the right way- there's no one size fits all.

Please let me know if you have any questions or need any support as you navigate this process.

Sincerely,

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AUTISM

A Beginners Guide

DIFFERENT THAN WHAT MOST PEOPLE THINK

WHAT IS AUTISM?

Autism is a Neurodevelopmental Disability that is characterized by differences in communication, socialization, and repetitive actions or patterns of thought. Autism is often very different than what most people think, and this is generally due to overgeneralization of stereotypes, as well as an increased knowledge of the full spectrum that the general public is not yet fully aware about. Autism is most often thought of in extremes from non speaking to savants, but the majority of individuals fall somewhere in the middle. Autism presents differently in each person, including a range of strengths and weaknesses as well as intensity of how they experience the world and their autism traits. In recent years, the neurodiversity movement has gained momentum, and adults diagnosed with Autism have spoken about their experiences which has allowed therapists and parents to learn, grow, and change how they think about the condition.

WHAT AUTISM IS:

Put simply, Autism is a difference in the brain that impacts how a person experiences and perceives the world around them. Individuals with an Autism diagnosis will have (or have a history of) some but not all differences in communication, socialization, and repetitive thoughts/restrictive behaviors listed below.

WHAT AUTISM IS NOT:

Autism is NOT bad or wrong. It does not mean anti-social, poorly behaved, or unintelligent. It does not mean a child will not make progress, communicate, have friends, excel in school, have a job, get married, or anything else. Autism is not a word to be avoided and is not anything to be ashamed of - it is simply a difference in the brain.

COMMUNICATION

May Have or Have History of:

- Delay in talking
- Delay in pointing
- Loss of words once acquired
- Decreased use of gestures
- Echolalia (repeating), scripting (repeating words from shows) or jargon after 2.5 years of age
- Strength in labeling items/nouns while difficulty asking for items or for help
- Pronoun errors
- Use unusual or made-up words
- Use words/phrases repetitively ("well", "actually", "literally"...)
- Takes things literally, struggles to understand jokes, sarcasm, homonyms, or idioms
- Shares facts, and has difficulty retelling events or stories
- Use formal speech, or difficulty matching language to listener

SOCIALIZATION

May Have or Have History of:

- Inconsistent use of eye contact, from avoidant to intense
- Prefer to play alone, decreased joint attention/showing items to share interest
- Difficulty initiating or interacting with peers, may be better with familiar people/adults
- Struggles expressing understanding of emotions
- Wants friends but difficulty making/maintaining friendships
- Difficulty participating in conversations (unexpected topic changes, excessive talking, interrupting, asks few questions about others' experiences)
- Difficulty understanding social cues: may need people to say what they mean rather than hint

REPETITIVE ACTIONS

May Have or Have History of:

- Struggle with changes, question changes (why?), or have preferred routines
- Play in the same manner (crashing toys, lining up, have a play routine that is repeated)
- Delay/difference in creative play
- Have preferred toys, topics, interests (can change with time)
- Focus on details, or need things to be perfect
- Sensory Differences: selective eater, struggles with hair washing/cuts, tooth brushing, nail clipping, sensitivity to or preference for certain sounds, looks closely at items or out of corner of eyes, hand flapping, finger posturing, jumping, seeks or avoids pressure/input

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THE AUTISM SPECTRUM

MANY PEOPLE THINK OF AUTISM AS LINEAR....
BUT THIS IS A COMMON MISCONCEPTION.

WHAT MOST PEOPLE THINK:

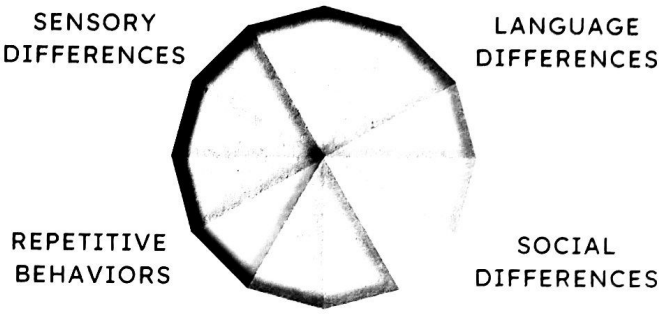
A LITTLE AUTISTIC

"HIGH FUNCTIONING"

EXTREMELTY AUTISTIC

"LOW FUNCTIONING"

WHAT THE SPECTRUM IS REALLY LIKE:



INSTEAD, INDIVIDUALS HAVE AREAS OF STRENGTHS AND WEAKNESSES
AND SIMILARITIES AND DIFFERENCES IN A VARIETY OF AREAS.

The Autism spectrum is not linear. We cannot point to a place on a line and say, "This is the level this individual is at." Likewise, we can't point to a place on a line and say, "This is the level the individual will be in the future." This is because individuals present in a variety of ways and have a range of strengths, needs, and/or areas of needed support. For example: Person A is very verbose with advanced language skills, has routines and rituals they adhere to 100% of the time, has an intense interest in geodes, is a selective eater with few other sensory differences, and wants very badly to have relationships but struggles to maintain them. Person B is non-speaking and uses an electronic device to communicate, has and maintains friendships, has high sensory needs that require noise canceling headphones and specific tag free clothing, adjusts well to changes in routine, and has a high interest in computer programming. Which of these would be "high functioning?" The truth is, we would not be able to categorize either based off of that information, and even if we had every single bit of information about Person A and Person B, including who has a successful high paying job they are able to manage and who has a job with support and accommodations, we still could not put them on a point on the line. This is because people, regardless of any diagnosis, are just not linear.

However, the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, (DSM-5) requires medical professionals to give a level of severity as part of the diagnosis. It is important for parents to understand that levels given are subjective and will not necessarily remain the same over time. Level 3 is given to children with "severe deficits" who require very substantial support, Level 2 is given when "marked deficits" are observed and children require substantial support, and Level 1 is given when children require support and have "noticeable impairments" without support in place.

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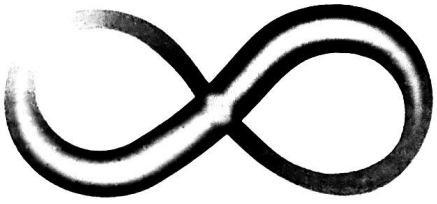
THE NEURODIVERSITY MOVEMENT:



The Neurodiversity movement focuses on the idea that individual brain differences in function and behavioral presentation (such as Autism and ADHD) are a part of the expected variation of the human population. This means Neurotypical brains are not "normal" and Neurodivergent brains are not "broken" - instead all brains are healthy and worthy. The Neurodiversity movement embraces and celebrates differences and focuses on inclusion, needed accommodations and support over finding a cure. Neurodiversity highlights differences and abilities rather than deficits and inabilities, as well as the value that Neurodivergent individuals bring to the world. Many adults with neurodevelopmental disabilities, as well as a growing number of therapists and interventionists, are very supportive of this approach to brain differences. The rainbow infinity symbol is the sign for Neurodiversity. Many adults diagnosed with Autism prefer this symbol over the popularly used puzzle piece. Many people feel the puzzle piece symbolizes there is something missing from a person and that a person diagnosed with Autism is a puzzle to be solved.

THESE CHARACTERISTICS DESCRIBE ME:

It's common for parents to see autistic-like characteristics in themselves when reading and learning about Autism after their child was referred for assessment. Many feel this is a reason for why their child is not Autistic. However, due to the strong genetic component, it's relatively common for parents to realize they are likely Autistic and just never received a diagnosis, or did not have enough characteristics to receive a diagnosis. Many choose to get evaluated and others self-diagnose or don't seek an evaluation because they do not need any accommodations. This can actually be very comforting to parents because it helps them realize that their child can be Autistic and be successful and have a family- just as the parent did.

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THE STRENGTHS IN AUTISM:

Autism is often talked about and portrayed in a negative light. Living with an Autism Spectrum Condition can be difficult and/or challenging for many people, but it's also crucial to talk about and be aware of the positives and strengths commonly seen in Autism. Just like all characteristics are not seen in each individual, all strengths will likely not be seen in each person. It's common for strengths in these individuals to be easily missed or overlooked due to a focus on weaknesses and areas of need. Similarly, Autism may be overlooked due to a person having a lot of strengths. Finding a child's strengths and building on their interests is key for progress. The following are commonly seen strengths:

- EXCELLENT MEMORY SKILLS: May remember words from books, directions in travel/maps, experiences, passwords, etc.
- HYPERLEXIA: May learn numbers and letters early, and/or teach self to read (often without adults even realizing).
- HYPERFOCUS: May be able to hyper-focus in areas of interest, spending hours experimenting and learning how items work, may know many facts or have extensive knowledge about specific topics.
- ATTENTION TO DETAIL: Often overlooked as a weakness for "missing the big picture," but many individuals are very observant, thorough, and detail oriented.
- VISUAL LEARNER: May have a good visual memory, think in pictures, or have picture memories.
- ANALYTICAL: May have excellent, methodical problem solving skills, and see patterns that others miss. Often excel in math, science, technology, or engineering.
- CREATIVE THINKING: May think "outside of the box" to create amazing works of art, stories, or problem solve in unique or unexpected ways.
- STRONG SENSE OF JUSTICE: May avoid telling lies, be very loyal, be a rule follower (although generally not societal/social rules), and have a strong sense of what they perceive to be right and wrong.
- ACCEPTING OF OTHERS' DIFFERENCES: Generally not judgmental, and very tolerant of differences.

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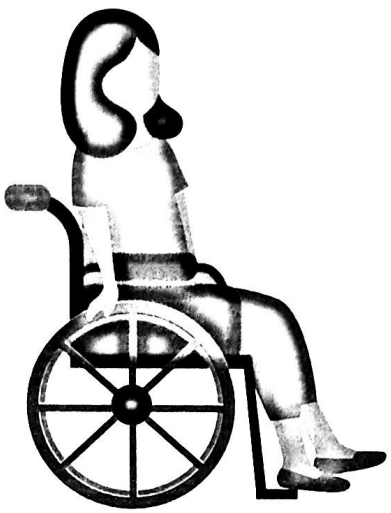
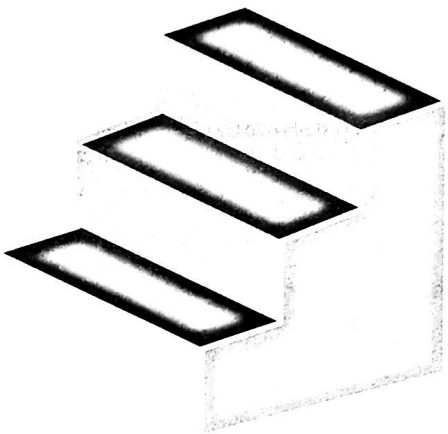
MEDICAL VS SOCIAL MODEL OF DISABILITY:

Medical Model = The Problem



The medical model is how most people view disability. It is what is taught in the vast majority of universities and focuses on an individual's deficits. The "problem" or "impairment" lies in the individual and their disability. For example, a person in a wheelchair cannot go up stairs = the person and/or wheelchair is the problem. Most medical providers (and diagnosing language) use the medical model to describe Autism and a person's differences and difficulties, and as a result is often used in assessments. It is common for interventions to be designed to "fix" the person, eliminate causes of disabilities, or make a person appear more Neurotypical.

Social Model = The Problem



The social model is more inclusive of differences and identifies outside barriers as the cause of difficulties. The "problem" is the environment not the individual, such as social barriers such as inaccessible buildings, languages, communication styles, services, attitudes, and discrimination. With our example above, the person in a wheelchair is NOT the problem, the stairs are the problem - access to a ramp or elevator would be accessible to everyone. Many people feel the true answer is in a combination of the medical and social models. We need to change the environment while also supporting individuals' needs through direct therapy and intervention.

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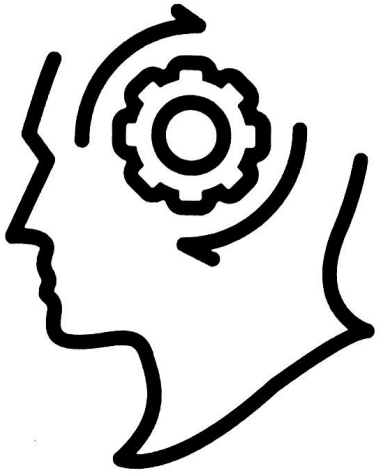
REFRAMING OUR THOUGHTS AND LANGUAGE:



Slowly but surely, the Neurodiversity movement is helping the world to reframe how they view Autism as well as other disabilities. However, changing how the world views a topic is not an overnight event. Due to this, many clinicians and physicians are being taught only the medical model of disability, and most of the academic verbiage seen is based off of the medical model. Parents see terms like "alarming increase," "pandemic," "red-flags," "deficits" when they look up Autism. Terms like this only add to the stigma that surrounds Autism and makes parents fearful about a possible diagnosis for their child. Instead, language such "expected increase based on what we have learned about Autism," "characteristics," "traits," and "differences" are considered more accurate. How we think and talk about Autism with others can have a significant impact on children and how people around them view children with differences or disabilities.

PERSON FIRST VS IDENTITY FIRST LANGUAGE:

Many people wonder how we should refer to individuals with an Autism diagnosis. Do we use Person First Language (person with Autism) or Identity First Language (Autistic person)? The answer depends on the individual's preference. In college and graduate school, most clinicians were taught to use person first language to signify that the child is a person first and more than a diagnosis. However, many adults on the Autism Spectrum have been vocal about their (general) preference for identity first language. Most Autistic adults feel Autism is part of their identity (not something that can be separated from them) and not a disease (like cancer) that should be cured or fixed. Just as one would not say they are a person with intelligence or tallness, and would describe themselves as intelligent or tall - many Autistic adults prefer identify first when talking about their Autism. The growing Neurodiversity movement values neurodivergence and this has allowed Autistic adults to develop what is best described as their own culture, similar to the Deaf community. Many feel that Autism is only a disability because the world around us is built and geared towards Neurotypical people (social model of disability). As with anything, there is disagreement within the Autism community, which is why individual preferences should always be taken into consideration.

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IS GETTING AN AUTISM EVALUATION IMPORTANT?

The decision to pursue an Autism evaluation is completely up to the parent or guardian, and part of this decision should be knowing the benefits and possible drawbacks of seeking an evaluation. First and foremost, it's important to remember that a child is the exact same with or without an evaluation or diagnosis. Meaning they will have the same areas of strength and weakness regardless of if a piece of paper describes those as Autism or as any other condition. However, knowing the child's strengths and weaknesses can give invaluable insight to the child, as well as how they may best learn, and how the adults in the child's life can continue to support their growth and progress. It may help adults understand why a child acts or behaves the way they do, or may reveal some accommodations that may help support the child. In some locations, a diagnosis may help get insurance to cover certain therapies. Most importantly, knowing a diagnosis can help a child (or adult) better understand and accept themselves and their neurology. Adolescents and adults who learn of their Autism diagnosis have reported it to be freeing to have a reason for why they are different, and this can have a positive impact on their mental health. Many individuals, especially females, do not get a diagnosis until their teens or early twenties, often when they are having mental breakdowns, engaging in self harm, diagnosed with eating disorders, and/or experiencing significant depression and/or anxiety that can lead to suicidal thoughts. This generally occurs due to burnout from years of masking, or trying to appear typical. A diagnosis can help an individual understand that nothing is wrong with them; their brain is simply different. If teens and young adults with late diagnoses had known earlier, if they were diagnosed correctly at a younger age, would it have made a difference in their experiences? Could intervention and education about Autism have helped? It's hard to know for sure, but many people feel that yes, knowing earlier could potentially help.

Possible drawbacks of getting a diagnosis include the possibility of misdiagnosis. Children are misdiagnosed as having an Autism Spectrum Condition when one is not present, and children are also misdiagnosed as having other conditions such as Attention Deficit Hyperactivity Disorder (ADHD), Generalized Anxiety Disorder (GAD), Language Disorder, Sensory Processing Disorder (SPD), Intellectual Disability (ID), Specific Learning Disability (SLD), Social Communication Disorder, Emotional/Mood Disorders, Obsessive Compulsive Disorder (OCD), Epilepsy, or a combination of these diagnoses when an Autism Diagnosis would be more accurate. These conditions are often present in addition to an Autism Spectrum Condition, and it's relatively common for a child to have two or more of the listed conditions as a part of an Autism Diagnosis. Autism Spectrum Condition is a commonly preferred term by the Autistic community over Autism Spectrum "Disorder". This is where second opinions and re-evaluations at a later age can be helpful if a parent or guardian questions a diagnosis. An Autism diagnosis will not prevent a child from attending college (although may make them eligible for accommodations in college if needed), but is included in a long list of diagnoses and conditions that could prevent them from serving in the military.

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HOW TO GET AN AUTISM EVALUATION:

There are many options for families to get an Autism evaluation. In the U.S., some options vary by state and location such as the ability to get an evaluation through Early Intervention (birth - three, free evaluations), and the local school district (ages 3-21, free evaluations). Call the Early Intervention center for your county or public school home campus for information specific to your area. You can also talk to your healthcare provider to request a referral for an evaluation by a professional who specifically specializes in Autism evaluation such as a developmental pediatrician, neurologist, psychologist, or psychiatrist. A team approach is an excellent option where multiple professionals work together to determine the presence or absence of an Autism Spectrum Condition. These professionals can bring unique backgrounds to look at the child as a whole and may also include a Psychologist, Speech Language Pathologist, Occupational Therapist, Diagnostician, or Behavior Specialist. Many people feel their concerns are dismissed by family members, pediatricians, and therapists, so it's important to trust your gut when seeking a specialist and asking for referral even if others do not feel it is necessary.

EDUCATIONAL ELIGIBILITY:

An Educational Eligibility is based on state eligibility requirements, and the definition for Autism varies by state. The Individuals with Disabilities Education Act (IDEA) defines Autism as a developmental disability that significantly impacts: verbal communication, nonverbal communication, and social interaction. It lists other characteristics that include: engagement in repetitive activities and stereotyped movements, resistance to change, and unusual responses to sensory experiences. To qualify for the educational eligibility, a child must meet requirements set forth in the state's definition and demonstrate an educational need for services. It is important to know that educational need is not limited to academic need. However, it is possible for a child to qualify under the definition of Autism, but not demonstrate an educational need for services and therefore not meet eligibility. Caregivers can request a special education evaluation by sending an email that states, "I am formally requesting an evaluation for [Autism, Speech, etc]."

MEDICAL DIAGNOSIS:

A Medical Diagnosis is given based on a list of "symptoms" in the Diagnostic and Statistical Manual Of Mental Disorders - 5 (DSM-5). A person would need to have "persistent deficits" in social communication and social interaction in three areas including 1. Social-emotional reciprocity, 2. Nonverbal communication, and 3. Developing, maintaining, and understanding relationships. In addition, one would need to exhibit at least two restricted, repetitive patterns of behavior, interest, or activities: 1. Stereotyped or repetitive motor movements, use of objects, or speech, 2. Insistence on sameness or routines, or ritualized patterns of nonverbal or verbal behavior, 3. Highly restricted, fixated patterns of interest, 4. Hypo or hyper sensitivity to sensory aspects . In order to meet diagnostic criteria, the "symptoms" need to cause clinically significant impairment in social, occupational, or other important areas of functioning. Medical assessments are generally completed in outpatient settings and conducted by a medical physician or psychologist. Often, a medical diagnosis is needed for insurance purposes.

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WHAT TO EXPECT IN AN EVALUATION:

Autism evaluations can look different depending on where a person is evaluated and who is doing the evaluation. This would be an excellent question to ask your evaluators prior to your child's assessment. It's important for caregivers to know that an Autism evaluation should be based off of more than one one single component. Autism is diagnosed based on presence of characteristics, and there is no one test that confirms Autism with 100% accuracy; therefore information should be taken from multiple sources. Family members can generally expect an interview with the guardian and/or teacher/caregiver, rating scales, observations, and direct assessment and interactions with the child. It's good for caregivers to be prepared to be asked many questions, some of which you may not understand. It's okay to ask for clarification when you aren't sure what the examiner is asking. You know your child best and can give great insight into how they go about their regular days as well as detailed information about their development- all of which is incredibly important.

The Autism Diagnostic Observation Schedule, Second Edition (ADOS-2) is the most commonly used direct assessment at this time, with the Childhood Autism Rating Scales 2 (CARS-2) the second most common, but there are many other options available. Most assessments are semi-structured and play based for younger children. Due to this, most children really enjoy the Autism assessment pieces. Some children may tantrum due to unexpected or unfamiliar events or transitioning from a fun activity to the next. The examiners are used to this, but please let them know if it is typical or not for your child if that happens. Older children may have some more interview style elements to their assessment.

For most Autism assessments for young children, parents or guardians are often invited to attend. Often caregivers will see an activity such as doing a puzzle and think the assessors are looking to see if the child can complete the puzzle. In reality, the child does not really need to complete the puzzle and could even throw the pieces all over the room and not receive an Autism diagnosis. This is because evaluators are not looking to see if a child can complete an activity, but how they interact while they do activities. This is why it's important for caregivers who attend their child's assessment remember to try not to tell their child what to do, unless specifically asked by the assessment personnel. Assessors want to see what a child can do on their own- not what they can do with prompting. Many caregivers get nervous during these assessments, which is understandable, and this often results in over-prompting of the child. If your child is not acting in a typical manner, let the evaluator know how they typically respond. It's also key for many caregivers to understand they cannot "teach" a child how to "pass" an Autism assessment, and should not attempt to teach them how to take a test.

Most evaluations will include assessments in addition to Autism specific assessments including academic/achievement, intelligence, and language assessment. This can help gain an understanding of the child as a whole as well as help with making a differential diagnosis. In some places you may get results immediately and others you may need to wait before you get the results. You can ask your evaluator when to expect results to relieve some anxiety.

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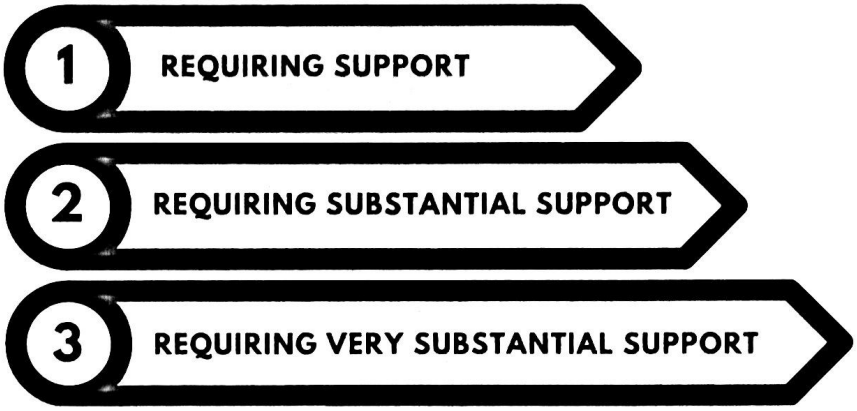
LEVELS OF AUTISM:



As part of a medical diagnosis, most evaluators using the Diagnostic and Statistical Manual of Mental Disorders 5 (DSM-5) give a severity of Autism as part of the diagnosis. This is reported by giving a person diagnosed with Autism one of three levels. It's important to note that levels are not always accurate across skills, settings, and/or over time, and many professionals and Autistic adults feel levels or functioning labels (high or low functioning Autism) are not helpful descriptors. Most people cannot fit into a box of functioning levels, and feel a more specific description of abilities would be more accurate. An example could be "Sally has average language skills, but requires support with self-advocacy, problem solving, and with changes in routine," or "Jackson enjoys reading and is currently nonspeaking and uses a device to help him communicate, he requires noise canceling headphones and support with self regulation." Below are the criteria for the levels, but please note the DSM-5 is based off of the medical model of disability, which focuses on impairments and does not use Neurodiversity friendly language.

- **Level 1, Requiring Support:** Without support, deficits cause noticeable impairments. Has average to near average language skills but struggles with pragmatic or social language such as participating in conversations, and difficulty with social interaction. May have difficulty with change and/or organizational difficulties that interferes in at least one context.
- **Level 2, Requiring Substantial Support:** Has marked deficits in communication and social skills such as difficulty speaking about non preferred topics or abnormal responses to social overtures. Difficulty with change or restricted interests that is obvious to the casual observer and interferes in a variety of contexts.
- **Level 3, Requiring Very Substantial Support:** Severe deficits in verbal and nonverbal functioning, very limited invitations and responses to social overtures. Extreme difficulty coping with change and has restricted interests or repetitive behaviors that interfere in all settings.

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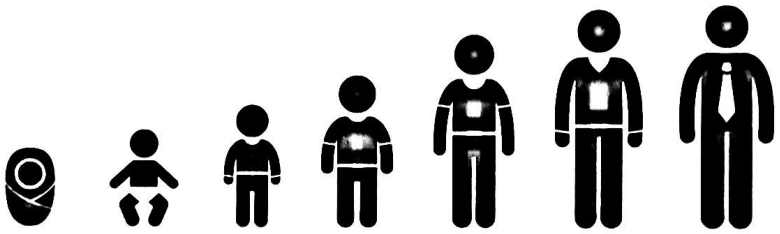
WHAT AGE IS IDEAL FOR EVALUATION?



There is no one ideal age for evaluation. An evaluation should be completed as soon as any one person thinks one is necessary, and parents should not have to wait until a specific age (such as 3-5 years) before they can get an evaluation. Generally, evaluations can occur around 12 months of age through adulthood. Many parents worry that early Autism diagnoses will not be accurate because of a child's young age. Research shows that children given a diagnoses of Autism at 18 months of age remain stable over time. Alternatively, 1/4 children diagnosed with language delay only at 18 months were later diagnosed with Autism. This means that while early diagnosis is generally accurate, children tested but not given a diagnosis at an early age may get diagnosed once characteristics are clearer at an older age. If a diagnosis (or lack of diagnosis) is ever questioned, a re-evaluation should be completed.

I WAS TOLD TO WAIT TO GET AN EVALUATION:

You are not alone. Many parents have been told to wait. And sometimes, waiting is okay - for a time. As mentioned above, there is not a magical age that is best for an evaluation. Generally, it is reasonable (although certainly not necessary in all cases) to wait until 18 months of age, but after that time-frame, recommended waiting due to age alone is not supported by research. For example, "we have to wait until the child is 3, 4, or 5 years of age" is simply not accurate and is outdated information. If you feel like your child needs an evaluation and a pediatrician or therapist recommends waiting and you are uncomfortable with waiting, it is okay to state your concerns and continue to request an evaluation, or seek an evaluation without a doctor referral if possible.

If you, as a caregiver, would like to wait on an evaluation, it is recommended that the child have access to all areas of needed support (such as speech therapy, occupational therapy, academic support, etc) while you wait. There aren't a lot of benefits to waiting except to give the family time to process, but getting a diagnosis can help the individual, family, teachers, and therapists better understand a child and their needs. Also, there are often long wait times to obtain an evaluation. Is is usually best to begin the process when concerns arise, rather than delaying.

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THESE "CHARACTERISTICS" ARE AGE APPROPRIATE:

It is true that many characteristics of Autism are typically seen in development. For example, infants wave their arms about when they are excited and it looks like hand flapping. Many young children struggle to engage in reciprocal conversations as they are learning how conversations work. Most children have their favorite toys/movies/topics to talk about. But where is the line between what is typical and what is not?

It's hard to say exactly because so many things are typical.... until they aren't. Each person is different, but specialists will look at the frequency (how often things happen), the quality (what it looks like, or how a child interacts -rather than a yes/no "Do they interact?"), and consider the child as a whole. Most children will demonstrate 1-2 characteristics, but in order for it to be Autism, a person would need to have a combination of characteristics.

While these will not guarantee an Autism diagnosis, some specific reasons to get an evaluation regardless of areas of strength include: Language regression of more than 10% of words, echolalia/scripting after the age of 2.5, child is able to label items (or knows all their ABC's, numbers, colors) but struggles requesting wants/needs, if the caregiver or therapist has concerns in two or more areas of Autism (language, sensory, socialization, or repetitive actions,) significant difficulty with changes in routine, if a child is described as being "in their own world", or if anyone feels an evaluation is needed.

WHY ARE SO MANY PEOPLE DIAGNOSED LATER IN LIFE?

Many children and adults are not diagnosed until they are older. This often happens because some children are able to meet milestones while they are young (or as mentioned above- "it's typical until it's not"), and then struggle to "keep up" as they get older. This is because social demands increase with age. Young children are not expected to share all of the time or be interested in what others are talking about, but as kids get older, these skills are viewed as polite or "correct". For example, kindergarteners generally show interest in each other and play simple games like tag everyday, but by 3rd grade, kids play a variety of games at recess and become more social in nature, engaging in activities similar to pre-gossiping. Kids are also expected to recognize nonverbal social cues, engage in conversations with a variety of people about a variety of topics, and develop close friendships rather than the whole class being friends. Additionally, kids become less forgiving of differences and popularity becomes important. Another reason for late diagnosis is a misunderstanding of Autism. Many people are misdiagnosed with ADHD or Depression and later come to realize Autism is a better description of their characteristics and needs.

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MISDIAGNOSIS:

In 2020, the Centers for Disease Control (CDC) released updated prevalence (from data collected in 2016) for Autism Spectrum Disorder (ASD) and it was reported that 1 in 54 children are currently diagnosed. When broken down by gender, it was reported that 1 in 32 boys are diagnosed while 1 in 144 girls are diagnosed with Autism. This is an increase from 2012 data which reported the prevalence to be 1 in 69, and a significant increase from data taken in 2000 which reported Autism to occur in 1 in 150 children. Many people are alarmed by this increase and as a result, it is common to hear claims that children are being over-diagnosed. Supporting this theory, many parents report professionals diagnose their child solely to get insurance coverage for therapies. However, many people feel that the increase is due to many factors such as increased knowledge about the full spectrum and how it may present (which is supported by research), increased access to assessment, reduced societal stigma, as well as Autistic adults reproducing and having Autistic children. It may also be helpful to think about those numbers in a different way. Most people do not realize that 1 in 54 is equal to 1.8% of children. Many in the Autism community think the number will continue to rise and become more accurate by increasing to 5-10% of the population (1 in 20, or 1 in 10). The majority of professionals and Autistic adults agree that Autism is significantly under-diagnosed in the female population.

In reality, characteristics of Autism overlap with many other conditions, and as a result, it can be difficult for parents, therapists, and physicians to know which diagnosis is the most appropriate, especially without doing a full evaluation. Many parents, therapists, and physicians that are generalists (work with a variety of children/needs) feel pressure to know the correct diagnosis before referring children for evaluation, which is not necessary. If there is any question, referrals should be made so that evaluators specially trained in evaluations can differentiate between similar diagnoses. Diagnoses with similar or overlapping characteristics include: Attention Deficit Hyperactivity Disorder (ADHD), Generalized Anxiety Disorder (GAD), Language Disorder, Sensory Processing Disorder (SPD), Intellectual Disability (ID), Specific Learning Disability (SLD), Social Communication Disorder, Emotional/Mood Disorders, and Obsessive Compulsive Disorder (OCD). It's a good idea for a child with more than one of these diagnosis (e.g. Language disorder + Sensory Processing Disorder) to have an Autism evaluation in order to rule it in or out.

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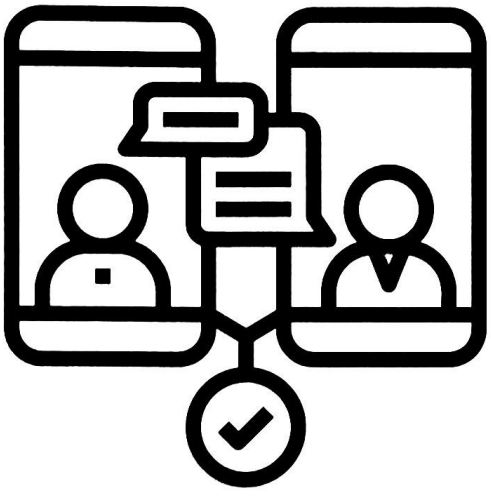
SECOND OPINIONS:



If for any reason you are not completely comfortable with the initial assessment results, a second (or third!) opinion is an excellent next step. Many people need to see results from two or more separate evaluators before they are confident in a diagnosis - or lack of diagnosis. Sometimes families did not feel the first evaluation was complete or did not consider all information, and at times, caregivers are not confident in assessment personnel's abilities.

Whatever your reasoning, second opinions are completely okay to seek. There is no shame in wanting a second opinion. Caregivers have several options when it comes to second opinions including when to do them and where to get them. Many people choose to do another evaluation immediately, while others choose to wait. This is completely up to the caregivers, but it is important to know that sometimes it is easier to correctly identify kids at an older age. This allows the child to have time to learn and grow with interventions they may need, as well as gives evaluators a chance to better differentiate between Autism and other diagnoses that are generally given at older ages (such as ADHD, or other Learning Disabilities). Caregivers may also want to consider choosing an evaluator with a good reputation for thorough and complete evaluations, which often comes with a longer wait list. Team based assessments, or assessments with multidisciplinary members (such as Psychologists, Speech Pathologists, Occupational Therapists, Educational Diagnosticians, etc.) are also good options for second opinions because they involve multiple team members coming to the same conclusion in order to give or not give a diagnosis. If your child was evaluated by the school district and you disagree with the results, refer to your state's procedural safeguards or ask your school contact about options for getting an outside independent evaluation.

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BUT IT CAN'T BE AUTISM BECAUSE THEY.....

- MAKE EYE CONTACT
- CAN TALK
- CAN FOLLOW DIRECTIONS
- ARE SOCIAL
- PLAY CREATIVELY
- DO NOT HAVE MELTDOWNS
- ARE AFFECTIONATE
- MAKE PROGRESS
- ARE CREATIVE
- DO NOT FLAP OR STIM
- DON'T HAVE OBSESSIONS
- SEEM "NORMAL"
- ARE OKAY WHEN ROUTINES CHANGE
- DON'T LINE THINGS UP
- CAN READ
- HAVE A SENSE OF HUMOR
- HAVE ADVANCED LANGUAGE SKILLS
- PASSED THE MCHAT AT THE PEDIATRICIAN
- HAVE JOINT ATTENTION AND CAN POINT
- HAVE AND SHOW EMPATHY
- USE GESTURES
- ARE SMART
- PLAY WITH OTHERS
- GET ALL A'S IN SCHOOL
- ARE DIAGNOSED WITH (ADHD, ANXIETY, ETC)
- RESPOND TO THEIR NAME
- ARE JUST QUIRKY
- DON'T WALK ON THEIR TOES
- ARE HAPPY AND RARELY UPSET
- HAVE FRIENDS
- JUST HAVE SOCIAL ANXIETY
- DON'T COVER THEIR EARS AT LOUD NOISES
- ATTENDED COLLEGE
- HAVE A JOB
- PARTICIPATE IN CONVERSATIONS
- ARE TOO YOUNG TO BE DIAGNOSED
- MET ALL OF THEIR DEVELOPMENTAL MILESTONES
- EAT AND SLEEP WITHOUT DIFFICULTY
- ARE DEVELOPING JUST LIKE THEIR PARENT, WHO IS JUST FINE

AUTISTIC PEOPLE CAN DO ALL OF THE THINGS

Many of the above items listed are common, albeit stereotypical, characteristics of Autism. Many of them are factually incorrect (such as Autistic people cannot be smart). All people with an Autism diagnosis will present differently and the vast majority do not have all of the possible characteristics. They also can make progress so that while many skills are commonly delayed (such as joint attention, pointing, or responding to name), many children achieve or demonstrate these skills and milestones at a later timeframe. While it's highly unlikely that an Autistic person would demonstrate all of the skills listed above, demonstrating several of the listed skills is likely. There is no one (or even several) skill or strength that a person could do that would mean a person could not have an Autism diagnosis.

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SERVICES AVAILABLE IN THE US:

There are many options available for support and intervention for kids with and without an Autism diagnosis. The most common options are: Early Intervention, public school services, or private practice services. Children have to be pretty significantly delayed in order to receive services such as speech, occupational therapy, or physical therapy through Early Intervention and School-based services, so private intervention through insurance may be the best route for many. Caregivers can also decide to do a combination depending on what is right for their child.

EARLY INTERVENTION:

Early Intervention is a term used to describe publicly funded services and supports available to children and their families in the United States from birth to age 3. Evaluations though Early Intervention are free, and if a child qualifies, intervention may be provided for free or on a sliding scale depending on your state. Families do not need a referral from a physician, and you can find services in your area by googling your state or county and Early Intervention. Services start with an evaluation to see if a child is eligible for services, but you can also look up lists of automatic qualifiers (such as medical diagnoses). If a child is eligible, an IFSP, or Individualized Family Service Plan, will be created and implemented. The IFSP will outline the services and goals a child will be working on while they are in Early Intervention. It's important for caregivers to know they have a voice in creating the IFSP.

PUBLIC SCHOOL SERVICES:

Public School Services are available to children from 3-21 years of age who meet eligibility as a student with a disability. Some children enrolled in home school and private school may be eligible for services as well. If you are unsure how school-based services work in your area, you can call your child's home campus they would attend if going to school. Caregivers can request an evaluation in writing (can be an email), and the school should get back to you in a timely manner (timelines may vary by state, but usually less than 3 weeks). The school will conduct an evaluation in all areas of concern, and will complete an FIE or Full Individual Evaluation laying out a child's evaluation results and possible area(s) of eligibility. Once this is completed, an Individualized Education Plan (IEP) meeting will be scheduled.

An IEP is a plan that will decide services, goals, and accommodations needed in order for a child in Special Education to be successful in school. IEPs are individualized and should be tailored to meet each child's individual needs, so as a result most IEPs will not look the same. IEP meetings can sometimes be emotionally difficult for caregivers because even though strengths are reviewed, they tend to focus on areas of need and weakness and how they can support the child in those areas. Parents are a part of the IEP team and have a voice in making this plan. Parents have the option to agree or disagree with the plan at the end of the meeting. The school should provide you with your rights (Procedural Safeguards) and parents should refer to that if they have any questions or disagree with the school's results or recommendations.

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COMMON SCHOOL ACCOMMODATIONS:

An accommodation is a change in the environment, curriculum format, or additional equipment that allows an individual with a disability to access content or complete work. Accommodations can change how a child learns the material, but they are responsible for learning the same material as everyone else. For example, having information read aloud or via audiobook: The child is still exposed to the same information, just in a different format. This is different than a modification, which would change the content of what the child is taught. For example, shortened assignments or alternative homework.

Many people view accommodations as a "special treatment" that gives one an advantage over others, or as a "crutch" that they will come to depend on. A better way to view this is as a way to level the starting point for children with and without disabilities. A good example is a hearing aid. Most can agree that giving a Deaf/Hard of Hearing child a hearing aid is a needed accommodation to help a child access information in a similar way as other students and not as special treatment. Learning accommodations are the same as they allow children to access information in a way that sets them up for success. Not all children with a disability will need every available accommodation, which is why parents and school staff should decide together which are needed for a child on an individualized basis. Common accommodations include:

- Sensory breaks
- Allow use of fidgets
- Advanced notice of changes in routine
- Visual Schedules
- Graphic Organizers
- Access to quiet work environment
- Allow for wait time
- Offer a variety of ways to respond to questions
- Offer a variety of ways to demonstrate understanding of concepts
- Provide written instructions
- Chunking of work (break down larger assignments into more manageable tasks)
- Clear, concise directions
- Direct teaching of nonliteral language
- Color coded systems to support organization
- Frequent breaks/movement breaks
- Give choices when possible
- Access to calming area
- Note taking assistance
- Extended time for tests/assignments
- Allow access to preferred peers for group work
- Visual timers
- Preferential seating for where the child best learns
- Check for understanding with specific feedback (Demonstrate understanding either verbally or with actions vs "Do you understand?")
- Access to noise cancelling head phones
- Use interests and strengths in assignments when possible
- Directly teach self advocacy skills
- Flexible seating options, including option to stand to work
- Opportunities to access preferred adults
- Reduced work if understanding has been demonstrated
- Access to Assistive Technology (Text to speech, AAC, etc)

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COMMON HOME ACCOMMODATIONS:

PART 1

Many children benefit from accommodations at home. Not all children will benefit from each of these accommodations, and parents are encouraged to make decisions about their child's needs on an individualized basis. Common home accommodations include:

COMMUNICATION:

- Accept all forms of communication (words, signs, pictures, gestures, etc).
- Offer choices to communicate wants/needs.
- Value and respect all communication styles. Provide access to pictures, sign language, or AAC device to support communication and model the child's chosen style.
- Allow for wait time for responses.
- Give clear directions with visual support as needed (pictures, word lists, etc).
- Check for understanding with specific feedback (Have them demonstrate understanding either verbally or with actions vs "Do you understand?").
- Clarify if figurative language is used by explaining and rewording.

SOCIAL:

- Accept each child's level of interest in others and don't force interactions if they do not want them. If they are interested, provide support as needed.
- Find peers with similar interests either online or in real life.
- Model how to inference others' perspectives.
- Explicitly state/label emotions in self, or characters in book/videos and explain how you can recognize feelings via facial expressions and body language.
- Explain "unspoken social rules" ("we don't tell people they are ugly because it can make them feel bad" vs "that's rude")

ROUTINES:

- Have a predictable home routine and stick to it as much as possible. This can be loosely to highly structured depending on what the child needs. It's recommended to have a consistent morning, afternoon, and evening schedule including meals and typical activities.
- Use visual schedules to aid for when changes in routine occur, and go over the visual schedule daily (even if no changes will occur that day) to build trust.
- Give advanced notice of changes in routine.
- Offer choices to aid in decision making.
- Use pictures, social stories, or videos to help children when changes may occur. This may be showing what a dentist office looks like, or what to expect at the airport.
- Use visual or auditory timers to aid in changing from one activity to the next, which will help with transitions.
- Break down activities into smaller chunks that the child can mark off as complete (such as when doing homework, chores, daily living skills like toothbrushing, etc).
- Color coded systems to support organization/calendar of events.

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COMMON HOME ACCOMMODATIONS:

PART 2

Tip: Caregivers (and other adults) should be flexible with expectations and accepting of a child's needs as valid. If something is upsetting or overly frustrating to the child, it may help to stop and think, "Is what I am expecting or requesting really what is important?" Rules that are there for safety are important and should not be flexible, but should be done in the least upsetting way possible. Primary caregivers may need to be explicit with these expectations with grandparents, etc.

SENSORY:

*Each individual's sensory needs are different. It is recommended families consult with an Occupational Therapist to incorporate sensory strategies at home.

- Access to calming or sensory area specific to the child's sensory needs.
- Access to sensory toys or fidgets.
- Do not force or require eye contact.
- Access to quiet work environment.
- Buy clothes of specific color, material, or tag-less/seamless items.
- Vacuum/use blender when child is away.
- Wash hair with a sponge to keep water off face and eyes.

- Common sensory specific tools:

1. Trampoline
2. Rocking chairs/ balance boards
3. Weighted blankets, lap pads, vests, etc
4. Noise cancelling headphones
5. White noise machine
6. Flexible seating: beanbags, wobble chairs, vibrating seat cushions, etc
7. Dimmable lighting options for bedroom
8. Tents/tunnels, tight spaces

SPECIAL INTERESTS:

- Find peers with similar interests either online or in real life.
- It's okay to encourage other topics/ideas but do not tell a child, "nobody wants to hear about _____" , or make a child feel like their interest is a burden to others.
- Encourage a child's special interests and use their strengths to help them with communication, coping skills, homework, and safety rules (i.e. add to picture schedules, social stories- "Thomas stays by his mom so he can be safe").

DIRECTLY TEACH COPING AND SELF ADVOCACY SKILLS:

- Teaching self advocacy:

1. Model and teach asking for help when needed.
2. Teach how to advocate for their needs and teach others about brain differences.
3. Teach explicitly what others taking advantage of them can look like (both peers and adults) and role play saying "no".
4. Accept "no" and a child's boundaries as long as it is reasonable to their safety.

- Teaching coping skills:

1. Teach and practice when the child is calm and regulated.
2. Model what this might look like when you feel overwhelmed - "I feel frustrated because this is difficult, I am going to get five pennies and count them as I take deep breaths."
3. Label your child's feelings when they are feeling overwhelmed, frustrated, happy, etc.

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AUTISM GLOSSARY:

PART 1

It's common for parents new to Autism to feel overwhelmed with all these new terms and information. Many people familiar with Autism but new to the idea of Neurodiversity may also feel confused with the vocabulary. Commonly used terms and their definitions:

- AAC: Augmentative and Alternative Communication (AAC) is communication supports used to supplement existing speech or give a person a functional way to communicate. AAC can be sign language, picture supports, communication boards, speech generating devices, or even line drawings that helps a person communicate.
- ABA: Applied Behavior Analysis or ABA is a type of therapy that applies the principals of learning and motivation in a systematic manner to change socially significant behavior by using strategies such as positive reinforcement and adjusting environmental variables such as visual schedules, timers, and using high interest toys to teach new skills.
- ABLEISM: Discrimination in favor of able-bodied people, including the belief that typical abilities are superior. Common examples include: lack of compliance with disability laws, buildings that are inaccessible, assuming disabled individuals want to be "fixed" or "cured," and assuming everyone has the same needs, accessibility, and limitations.
- ACTUALLY AUTISTIC: Often abbreviated AA, or Autist, this refers to a person who has been diagnosed with or self identifies as Autistic.
- ADOS: Autism Diagnostic Observation Schedule (ADOS-2) is the current gold standard Autism assessment.
- ALLISTIC: Refers to a person without an Autism Diagnosis. This person may or may not be Neurotypical.
- ASPERGERS: A previously used diagnosis under the Autism umbrella, often associated with a high intellectual ability. This diagnosis is no longer used and would now fall under the Autism diagnosis. It is not well supported by the Autistic community due to Hans Asperger's ties with the Nazis.
- DYSREGULATION: Difficulty managing emotional and sensory responses to the environment. This may result in meltdowns, and what often appears to others as overreactions to minor events. Dysregulated children should be supported during this time to help co-regulate rather than punished or ignored.

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AUTISM GLOSSARY:

PART 2

- ECHOLALIA: Repeating noises, sounds, words, or phrases heard. It is generally done with the same tone/pitch as the original sound and can be immediate or delayed. Echolalia has a purpose and should not be discouraged. It is also a positive indicator of future speech abilities. It is considered atypical development after 2.5 years of age, and the child may also be referred to as a gestalt language processor.
- EXECUTIVE FUNCTIONS: Cognitive capacities that enable independent, purposeful, and goal directed actions. Examples include organization, time management, persistence, resiliency, non-preferred task initiation, and mental flexibility.
- HYPERLEXIA: An early, very advanced ability to read words, often without any explicit instruction. It is often paired with an intense interest in letters and numbers. Children who are hyperlexic may read fluently and have some difficulty understanding what they read.
- IEP & IFSP: Individualized Education Program (IEP) is the plan developed by the parents and the school to help support a child through special education services Individualized Family Service Plan (IFSP) is developed between parents and Early Intervention professionals.
- JOINT ATTENTION: When two people share an interest or attention in the same object or activity. It is characterized by eye gaze or pointing as well as one's ability to communicate interest to the other person by nonverbal means. Strong joint attention is characterized by frequent shifts in eye gaze from person to person. However eye contact should never be forced.
- MASKING: A social survival strategy where one hides their true identity to imitate others and appear Neurotypical.
- MELTDOWN: Often looks like a tantrum, but generally not goal driven and frequently a result of loss of control due to dysregulation. Meltdowns are not attention seeking in nature and support should be offered during these times.
- NEURODIVERGENT (ND): A term referring to an individual who is not Neurotypical. Can include Autism, ADHD, Dyslexia, OCD, Gifted and Talented, and more.
- NEURODIVERSITY: The range of individual differences in brain function and behavioral presentation, which is part of the expected variation of the human population. Basically, all brains are different and this is a good thing.
- NEUROTYPICAL (NT): A person with a typically developing brain (i.e. not Neurodivergent).
- NONVERBAL/NONSPEAKING: Nonspeaking is the preferred term, and refers to children and individuals who do not have spoken words. Nonspeaking individuals should have access to AAC as they have a right to communication.

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AUTISM GLOSSARY:

PART 3

- PECS: Picture Exchange Communication System is a specific form of AAC used to support one's ability to request preferred items by giving a picture to another person. Many picture based systems are referred to as PECS but are not actually the PECS system. Many specialists feel PECS limits children by not giving them access to a robust vocabulary as communication is so much more than just requesting.
- PERSEVERATION: When a person "gets stuck" on a topic, thought, or idea. It may be related to a special interest or anxiety related. Most people perseverate at times, but for Autistic people, it can be very difficult to move on.
- POSTURING: Often referred to as finger or body posturing, this occurs when a person shapes and/or tenses their body in unusual ways. It may look like unusual shapes or crossing of fingers, to tensing up the face or whole body.
- PRAGMATIC LANGUAGE: A part of language that consists of how we use language to interact socially, how we use nonverbal language, and how we participate in conversations. Autistic individuals generally have different pragmatic language skills than allistics.
- PROPRIOCEPTION: Often called the sixth sense, this is the awareness of the position and movement of the body. Difficulty with proprioception may appear as poor balance, posture, and/or coordination, not recognizing one's own strength, and avoiding difficult movements like climbing or walking on stairs (often due to fear of falling).
- PROSODY: a part of speech that includes intonation, stress, and rhythm of speech. Autistic individuals often have an unusual prosody and may speak in a high pitched voice, a sing song voice, use rising intonation (when not asking questions), or sound monotone or robotic.
- RIGIDITY: Difficulty with change. May look like a person expecting things to happen the same way each time, difficulty with multiple interpretations of one word/action/idea, and overall difficulty with flexibility from expected events. Predictability and sameness brings comfort to many Autistic people, and lack of familiar routines may increase anxiety or cause meltdowns.
- SAVANT: To have advanced knowledge in a specific area, which may include music, art, science, math, or any other area. This is often thought of when people hear the word Autism, and is truly amazing, but is quite rare.
- SCRIPTING: Sometimes called "movie talk," scripting is a form of delayed echolalia where a child repeats what they have heard at a previous time. It may be from a movie, show, book, song, or something a person said in real life.

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AUTISM GLOSSARY:

PART 4

- SENSORY CRAVER: Also called sensory seeking, are individuals who crave a lot of sensory input. They may move about frequently, like to cause sounds or a sensation to happen repeatedly, may like to spin/jump/rock/flap, may unintentionally hurt themself or others due to moving fast and hard about, and may enjoy looking at objects move.
- SENSORY DIET: A plan of activities and/or accommodations to meet a person's individualized sensory needs. This is usually developed by an Occupational Therapist.
- SENSORY OVER RESPONDER: Also called sensory avoidant, or hypersensitive, are individuals who notice sensory input at a higher rate than others. They may struggle tolerating loud sounds, be a selective (picky) eater, dislike being messy, have difficulty wearing different clothes, and/or have difficulty with bathing or grooming.
- SENSORY PROCESSING DISORDER (SPD): A neurological condition in which sensory input (taste, sound, touch, etc) is not processed in the same way as most people. As a result individuals with SPD respond differently than most when faced with sensory input. Examples can be sensory under responsive (low response), sensory craver, and sensory over responder, or a mixture of two or more profiles.
- SPECIAL INTEREST: An area of intense interest, that may stay stable over time or change every few days or weeks. Special interests may take up a lot of time and energy and an individual may spend a significant amount of time learning and studying this topic. They might bring it up in conversations or play frequently. Special interests should be supported and encouraged.
- SOCIAL STORY: Individualized short stories that may help a child recognize social situations, stay safe, or know what to expect in a novel situation.
- SPLINTER SKILL: A strength in one specific area while having weaknesses in others. It can be across subjects (great at math, struggles with communication) or within a specific area (can label vehicles, while struggling to make requests).
- STEREOTYPY: Repeated movements, actions, thoughts, or words. Examples may be flapping of one's arms, jumping, finger posturing, repeating words or phrases, and more. It may not be clear or highly repetitive to fall under stereotypy.
- STIMMING: Self-stimulating actions that are repeated in order to stimulate the senses.
- VISUAL SCHEDULE: A visual representation/tool that can help a person know what to expect next. It can support children who struggle with changes, transitions, or experience anxiety thinking about possible changes, and can be written words, pictures, or drawings.

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THERAPIES TO CONSIDER:

There are many options when it comes to support and intervention for children diagnosed with Autism. Not all children need or would benefit from every therapy option, and parents should understand that they do have options; there is no one size fits all therapy for children with any diagnosis. In general, many Neurodiversity affirming therapists recommend starting with speech and occupational therapy evaluations (as many children diagnosed with Autism have delayed language and fine motor skills, and sensory needs), and then deciding from there what works best for their child and family.

PLEASE NOTE THAT AN AUTISM DIAGNOSIS DOES NOT MEAN A CHILD REQUIRES THERAPY. A NEED FOR THERAPY SHOULD BE DETERMINED BASED OFF OF AN EVALUATION IN EACH INDIVIDUAL AREA BY A SPECIALIST WITH SPECIFIC TRAINING AND/OR LICENSURE IN THAT SPECIFIC THERAPY.

- SPEECH THERAPY: Speech Language Pathologists work on a variety of skills in children with an Autism diagnosis. Common areas for pediatric services include language development (learning to communicate = both speaking and with alternative means of communication, and increasing what children can understand), as well as pragmatic or social language. SLPs can also work on speech sound disorders for children whose speech may be unclear, feeding, and swallowing disorders.
- OCCUPATIONAL THERAPY: Occupational therapists have a wide scope of practice. They frequently work on fine motor skills, and supporting sensory processing needs in children diagnosed with Autism. OTs also work on coordination, handwriting, feeding, self-care, play skills, visual perceptual abilities, attention span, and assistive technology.
- PHYSICAL THERAPY: Physical therapists work on improving gross motor skills such as sitting, standing, walking, jumping, and running. They also work on strength, endurance, balance and coordination, orthotics, body awareness, and flexibility.
- PLAY THERAPY: Play can be incorporated into a variety of interventions, but this is referring more to play based counseling, psychotherapy, or cognitive behavioral therapy. Typically provided by a psychologist or therapist, play therapy can support social emotional development and help children who experience anxiety, have mood differences, or have a history of trauma. Families should seek a counselor familiar with Autism Spectrum Conditions if their child was given an Autism diagnosis.
- MUSIC THERAPY: Music therapy is an evidence based practice that can support a variety of disorders and conditions. Music can provide predictability and consistency, which many Autistic individuals crave. Music therapy can support motivation, communication, self-regulation, anxiety and mood difficulties.
- HIPPOTHERAPY: Hippotherapy refers to how occupational therapists, physical therapists, and speech-language pathologists use evidence based practice and clinical reasoning in the purposeful manipulation of equine movement as a therapy tool to engage sensory, neuromotor, and cognitive systems to promote functional outcomes.
- ANIMAL ASSISTED THERAPY: This is different from Hippotherapy in that it focuses on a person's mental health. Participants care for and build relationships with horses or other animals, and often used to support emotional and mental health such as anxiety.
- APPLIED BEHAVIORAL ANALYSIS: ABA is a type of therapy that applies the principals of learning and motivation in a systematic manner to change socially significant behavior by using strategies such as positive reinforcement and adjusting environmental variables such as visual schedules, timers, and using high interest toys to teach new skills.

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CONSIDERATIONS WHEN LOOKING FOR THERAPY FOR YOUR CHILD:

To help parents make decisions for what is best for their family, the following information should be considered:

1. Is the amount of time spent in therapy appropriate for the child's age? Many people feel 20-40 hours a week of direct therapy is an overwhelming expectation for a young child. When children spend extended times at school or in therapy, does the child get free time where they choose the activity? Are they allowed to ask for and receive breaks as needed? Does it take away from family time or outings?
2. For toddlers and preverbal children, is the focus of intervention building foundational skills through playful interactions with parents and caregivers? Do providers and parents partner together to support the child's learning and development during daily routines and interactions? Can the parent be present?
3. Is the purpose of therapy to make the child less autistic or more neurotypical? Or is the purpose to facilitate acquisition of functional, relevant, and meaningful skills while focusing on the child's strengths and interests?
4. Is stimming allowed? Does the provider acknowledge that stims serve as sensory anchors that help regulate the child's nervous system? Stims should not be blocked, unless harmful, in which case they should be replaced with a safer stim.
5. Does the provider force eye contact or write eye contact goals, or do they focus on joint engagement in other ways?
6. Is there an emphasis on building a connection with the child before teaching new skills? Does this happen throughout therapy or just at the beginning?
7. Are the child's deep interests and sensory preferences taken into consideration when designing learning activities?
8. Are the child's boundaries respected by teaching and allowing/supporting communication of "no" and "stop?"
9. Who is working with your child the majority of the time they are in therapy or in the classroom? Is the person qualified to write goals in all of the areas they are addressing? And if not, are they consulting with a professional to address those areas of need (i.e. speech-language pathologist for communication goals, occupational therapist for fine motor and sensory integration goals)?
10. For a child who is non-speaking, minimally verbal, or in need of additional support, is augmentative and alternative communication (AAC) provided, used, and respected as being as beneficial as spoken language? Is the AAC robust or limited?
11. Do all professionals supporting your child work together as a team? Is there positive collaboration going on that includes parents, caregivers, therapists, teachers, and other professionals and support staff? Are older Autistic children/adolescents being included in conversations regarding their individualized interventions?
12. Does your child enjoy spending time with the providers who are supporting their learning and development? If therapy causes distress, parents should consider other options. Therapy should not be traumatic.

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APPLIED BEHAVIOR ANALYSIS (ABA):

APPLIED BEHAVIOR ANALYSIS: ABA is a type of science based therapy that applies the principals of learning and motivation in a systematic manner to change socially significant behavior by using strategies such as positive reinforcement (preferred toys, high fives, hugs, edible snacks or treats, etc) and adjusting environmental variables such as visual schedules, timers, and using high interest toys to teach new skills. ABA is often given or "prescribed" by evaluators as a "go-to" blanket recommendation following an Autism diagnosis. But ABA is not the only option for Autistic children.

Applied Behavior Analysis generally is provided by a Registered Behavior Technician (RBT). Registered Behavior Technicians must have a high school diploma, complete 40 hours of training, and pass the RBT competency assessment and exam. RBTs are typically in charge of running the intervention program developed by a Board Certified Behavior Analyst (BCBA). BCBAs have graduate degrees and are typically in charge of the assessment, goal writing, parent training, and supervision of RBTs. ABA is generally recommended 20-40 hours a week, which is significantly more than other available therapies.

WHAT ABA FOCUSES ON:

ABA aims to improve language and communication skills, self-care, focus, attention, memory, play and leisure, motor skills, social skills, and academics, while decreasing problem behaviors. ABA approaches these areas of development with a systematic approach by breaking down skills into smaller steps, and rewards the child for each step they complete. Common techniques used in ABA are Discrete Trial Training (DTT) and Natural Environment Training (NET). Discrete trials are generally more formal and typically occur at a table in a one-on-one setting. The child is asked to do specific units of skills a specific amount of times and then given a reward after each attempt or correct trial. Natural Environment Training is more relaxed and occurs when children are learning to apply skills to more naturalistic settings. ABA also aims to look at the function (or reason) for "maladaptive behaviors" and work to extinguish or replace certain behaviors with either more functional or more "socially appropriate" behaviors.

CONTROVERSY SURROUNDING ABA:

ABA has a very questionable and unethical history. Many therapists who specialize and have advanced degrees in specific areas (generally speech language pathologists, occupational therapists, and physical therapists) feel ABA encroaches on their areas of expertise and that goals in the areas of communication, feeding, and motor skills should not be targeted by someone with little training in the area. There is also some disagreement in the order in which skills develop and therefore should be addressed, as well as the functionality of commonly seen autistic traits such as echolalia, preferred topics, and stimming. Many Autistic adults have voiced strong opinions against Applied Behavior Analysis, stating that the end goal is to make children "normal" or neurotypical, when that is not a fair or reasonable goal. Autistic adults frequently share about ABA childhood experiences that were abusive, report ABA encourages masking and leads to a negative self image, and many report suffering from Post Traumatic Stress Disorder (PTSD) as a result from their experiences. Some of these negative experiences happened a long time ago and some are more recent. Alternatively, some Autistic adults and minors report positive experiences with ABA, and many parents of children attending ABA report beneficial results in their children. Supporters of ABA claim that practices have changed over time and are no longer unethical- with many claiming to be neurodiversity friendly. Because of this discrepancy, it can make decisions about participating in ABA difficult for many parents.

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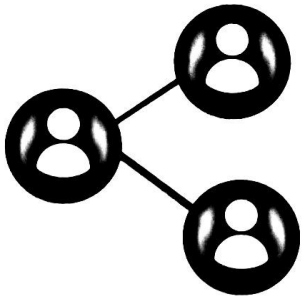
AUTISM AND SOCIAL SKILLS:



One of the most common misconceptions about Autism is that people diagnosed with Autism always prefer to be alone, and/or are anti-social. While it is true that many Autistic children do prefer to play alone, struggle to tolerate others in close proximity, or may have preferred people they will play or interact with, it's also common for Autistic children to be social in nature. Instead of viewing social skills as present or absent, it's best to view social skills from different angle. Instead of asking, "Are they social?" It's more accurate to ask, "How are they social?" Some Autistic children may be overly social, which may look like a lack of awareness of stranger danger (running up to unknown people, hugging strangers, oversharing personal information), difficulty recognizing boundaries or personal space, talking excessively to others (often struggling to read others' interest levels), and exaggerated body language or tone of voice. Some may struggle to pick up on more subtle social cues such as when someone is ready to stop a conversation or leave a social situation. Likewise, they may struggle to give subtle social hints and may come off as rude or abrupt in their statements and actions when that was not intended. Many Autistic children have difficulty reading social situations correctly or recognizing others' perspectives or motivations for their actions. Autistic individuals are often thought of as lacking empathy, but this is a myth. They may have difficulty understanding or expressing understanding of their own and others' emotions (because they generally process and express emotions in a different way than neurotypical people). Additionally, it may be important to the individual to have friends, but they may struggle maintaining friendships, or may only maintain friendships with other neurodivergent individuals.

During assessment, evaluators might look at the quality and quantity of eye contact, how a child engages in play with the parent or evaluators, how a person engages in conversations, and how they are able to observe and make inferences about others' thoughts, perspectives, and opinions. Reports are typically written using the Medical Model of Disability and focuses on deficits as compared to neurotypical communication standards, but it's important for parents to know that many of these are differences do not necessarily need to be "fixed" or addressed through therapy (like eye contact, or engaging in interactions/conversations the child does not wish to).

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STIMMING:

Stimming or stims are self-stimulating actions, sometimes referred to as stereotypical movements, and are actions that are repeated in order to stimulate the senses. Stimming occurs when a person repeats movements, sounds, visual stimuli, or words. Stimming can be tactile (licking/kissing/chewing unusual items, rubbing different textures/temperatures, teeth grinding), auditory (putting sound making objects close to ears, repeating sounds), visual (looking closely at items or through side of eyes, looking at lights or spinning objects), olfactory (smelling unusual items), vestibular (jumping, rocking, spinning), proprioceptive (pressure seeking/weighted objects), or a combination (hand flapping, finger posturing, verbal stims-humming, repeating sounds, and sometimes echolalia).

Stimming can help a person calm down, gain control, focus, destress, express emotions, prevent meltdowns, decrease anxiety, and more. Almost everyone stims in some way (nail biting, foot tapping, hair twirling) but neurodivergent individuals typically stim more frequently and as a way to self-regulate. Self-regulation is important and can support kids when they are overstimulated, under-stimulated, or experiencing strong emotions. Because self-regulation and meeting sensory needs are both so important, a person's stims should never be blocked or prevented. One exception is if a stim injures an individual or another person; in this case, it is recommended to attempt to find an alternate or safe stim. An Occupational Therapist may be able to support a family in these cases.

MASKING:

Masking is a social survival strategy where one hides one's true identify in order to imitate others and appear more Neurotypial. It is common in the Autistic population, and while anyone can mask, it's seen more often in females. It is possible for someone to mask without realizing they are masking (and to think that's how everyone feels/acts). People mask for a variety of reasons, including but not limited to: being seen as socially acceptable, to avoid bullying, to excel at or maintain a job, to avoid punishment for autistic like behaviors, to attract friends or romantic partners, to maintain safely (such as when interacting with law enforcement officers), or to avoid a stigma attached to some Autistic behaviors. There are some consequences to masking such as burnout, depression/anxiety/other mental health conditions, suicidal ideation or attempts, and delayed diagnosis (often not until they hit a crisis point). Adults can make attempts to decrease masking by accepting children for who they are and not trying to change them, considering if what you are teaching encourages masking, and giving a child the power to say no, choose when and when not to use taught social skills, and support and respect their decisions.

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AUTISM IN GIRLS:

Girls are frequently missed or misdiagnosed due to the fact that they often present differently than boys. Most assessments and the DSM-5 criteria were based off of how Autism presents in boys, and it is common for females to not meet diagnostic criteria due to differences in how features present. This is commonly due to the fact that they are more social in nature, are good at masking or pretending to be neurotypical, and internalize many of their feelings, and needs. It's important to note that males can present this way too, and those that do often go undiagnosed or misdiagnosed as well. Autistic girls are often only identified in teenage years or early adulthood, commonly due to mental breakdowns following years of masking. Girls are also more at risk for sexual abuse, so it can be helpful to identify them early, support their social needs, and teach self advocacy and bodily autonomy early on. Common characteristics seen in girls include:

- LANGUAGE DELAY: Often a late talker, or benefits from speech therapy at an early age. It is common for them to "catch up" by 5-6 years of age.
- ANXIETY: Often seen as social anxiety, and frequently viewed as the primary area of need.
- FRIENDSHIPS: May have friends, but be more of a follower, have a "mother hen," or be viewed as "bossy" and/or "direct."
- PERSONALITY: May be viewed as just naturally shy or quiet.
- FACIAL EXPRESSIONS: May have a flat affect (expressionless), or exaggerate or be overly expressive with facial expressions as if over-acting.
- TONE OF VOICE: May speak with a high pitched voice at a young age (similar to Minnie Mouse), sing-song voice, or unusual intonation.
- PERFECT: Often strive for perfection and described as a "perfect student" by teachers and coaches. This can often backfire with some extreme frustrations and meltdowns after school.
- SPECIAL INTERESTS: May have preferred topics that are typical for age and gender such as animals, princesses, nail polish, mini toys, etc.
- PLAY: May develop what appears to be creative play early on, but when closely examined, may be more setting up play scenes, or similar play routines repeated.
- CONVERSATIONS: May be good at responding to others and answering questions but struggles with initiating social interactions or asking questions about others' experiences.
- MASKING: Good at studying and imitating others in conversations and play (masking).
- SENSORY: Often present with sensory differences such as selective eating, sound/touch sensitivity, sensitivity to clothes/tags, and more.

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WHAT SEPARATES AUTISM FROM SIMILAR DIAGNOSES?

It's common for caregivers to want to try to figure out their child's correct diagnosis prior to getting an evaluation. While having a good idea of what evaluations your child needs is helpful, caregivers, teachers and even therapists do not need to try to differentiate diagnoses for children; that is why we have assessment specialists. Sometimes differentiating diagnoses is based off of subtle characteristics that non-specialists are not able to recognize, and some kids are just tricky to diagnose - even for those that specialize in assessments. However, a basic understanding of the differences may help adults understand and accept their child's evaluation results.

A key difference between Autism and other diagnoses is repetitive thoughts and actions, which are not included in most other diagnosis, other than Obsessive Compulsive Disorder or OCD, and sometimes seen in children with prenatal drug exposure or Fetal Alcohol Syndrome (FAS). This would include special interests, demonstrating a sameness in play, difficulty with changes in routine, preferring things to happen in just the right way, using words or phrases repetitively and/or echolalia and scripting past 2.5 years of age.

AUTISM

At its core, Autism is a social communication difference based on a constellation of characteristics: Differences in language, differences in socialization, and repetitive thoughts/actions with possible sensory differences. Traits specific to Autism include:

1. Difficulty understanding and explaining social rules and interactions
2. Differences in nonverbal communication (decreased gesture use, differences in facial expressions)
3. Language Disorder: Echolalia, scripting, or jargon after 2.5 years of age, language developing in atypical manner.
4. Repetitive body movements (flapping, body posturing or tension)
5. Preference for routines or sameness
6. Special or deep interests
7. Differences in development of play (delayed functional, symbolic, or creative play)
8. May be detail oriented, or often miss the "big picture"

ADHD

At its core, Attention Deficit Hyperactivity Disorder (ADHD) is a Executive Function disorder, characterized by differences in self-regulation, self-motivation, self-evaluation, and attention, and/or hyperactivity.

While many individuals diagnosed with Autism demonstrate the following, these characteristics are more specific to ADHD and include:

1. Lack of attention to detail
2. Difficulties maintaining focus to or initiating challenging or preferred activities or tasks
3. Organizational challenges
4. Easy distractibility
5. Forgetfulness
6. Differences in activity level (on the go, difficulty sitting still, restless, overly talkative)
7. Difficulty with impulse control (waiting for turn, interrupts, acts without thinking through actions)
8. May have language delays, meaning that develops in expected manner but on delayed time frame.

Many of the ADHD characteristics will also be seen in Autistic individuals, and many people meet criteria for both ADHD and Autism and get both diagnoses. Individuals diagnosed with ADHD alone generally do not have characteristics listed that are specific to Autism. Commonalities for both Autism and ADHD include: social differences, differences in eye contact, may have speech/language delays, sensory differences, attention difficulties, and difficulties with emotional regulation.

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AUTISM

Autism is based on a constellation of characteristics: Differences in language, differences in socialization, and repetitive thoughts/actions with possible sensory differences. Language based characteristics specific to Autism include:

1. Language development often has splinter skills, or skills that develop in an atypical manner. For example, a child may have strong labeling skills but struggle asking for items they want need. Language may be less flexible or they may have difficulty combining words in new ways. They may have advanced vocabulary for specific topics and struggle with grammar.
2. Often has limited gesture use, and delays in joint attention.
3. May demonstrate echolalia, and/or scripting past 2.5/3 years of age.
4. May lack inflection or speak with rising or unusual intonation/unusual pitch.
5. PLUS - differences in socialization, and repetitive actions/thoughts, restricted interests, or sensory differences.

AUTISM

One of the core characteristics of Autism - repetitive thoughts - encompasses sensory processing disorder, and the vast majority of Autistic individuals have sensory processing differences or difficulties. However, Autism is characterized by more traits including differences in language, socialization, and repetitive thoughts. Examples include:

1. Differences in language: Language delays or disorder, echolalia, scripting, or repetitive language persisting after 2.5/3 years, delayed pointing/gesture use.
2. Differences in socialization: Difficulty or decreased interest in engaging with others, difficulty maintaining conversations and/or friendships, may be overly or "inappropriately" social.
3. Repetitive thoughts, actions, or restricted interests: repetitive play, preferred toys or topics, special interests, struggles with changes in routine, etc.
4. Sensory differences are often repetitive in nature. For example: flapping, jumping, spinning, listening to sounds repetitively, looking at items very closely or out of corner of eyes, watch parts of films on repeat, and more.

LANGUAGE DELAY

A Language Delay occurs when a child's language develops in a typical manner, but on a delayed timeframe. It may be a stand alone condition or associated with another condition, and can also be present in Autism. Characteristics of Language delay:

1. Generally has strengths in joint attention (eye contact, following another's point or gaze) and gesture use to compensate for delays in vocabulary.
2. Frequently points to show interest in items out of reach (not just to request), and initiates shared interest in play.
3. Play develops and progresses in a typical manner.
4. Understands social rules and situations, although may have some difficulty engaging due to communication difficulties.

*Children who receive an Autism Diagnosis may be able to demonstrate the skills listed above. Both may demonstrate a strength in receptive language skills (what they can understand) and struggle with expressive language (what they can communicate). Children with language delay alone generally do not demonstrate differences in repetitive thoughts.

SENSORY PROCESSING DISORDER

Sensory Processing Disorder (SPD) is a neurological difference in how the brain processes sensory information. It can present as a sensory craver, sensory over responder, sensory under responder, or a combination of the three. It is commonly seen in individuals with Autism diagnoses as well as ADHD and anxiety, but is currently not a stand alone diagnosis recognized in the DSM-5. While most people have some sensory differences, it generally needs to impact everyday functioning in order to receive treatment. Individuals with SPD may:

1. Cover ears to loud sounds, or seek loud sounds.
2. Not respond to their name or environmental sounds although hearing is within typical limits.
3. Demonstrate high or low pain tolerance.
4. Be a selective eater.
5. Be selective about clothing: materials, tags, etc.
6. Dislike hands or body being dirty, or not appear to notice being messy.
7. Avoid touch, or seek tight pressure/input.
8. Have difficulty with bathing/hair washing, teeth brushing.
9. Struggle with potty training.

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SHOULD I TELL MY CHILD ABOUT THEIR DIAGNOSIS?

This decision is completely up to the parents, but it is strongly encouraged that parents consider telling their kids when they are old enough to understand about their diagnosis. A majority of Autistic adults explain that getting a diagnosis (even if they get it as an adult) can be freeing to help them understand themselves better. Many will share that they knew they were different from a young age, and that knowing why they are different, having a name for it, as well as having an opportunity to connect with others like them, can help to prevent future mental health problems. Knowing when to tell your child can be tricky, but it's important to always presume competence and begin exposing them to the idea even if they aren't fully able to comprehend. This can happen around 4-5 years of age, and older children can be told soon after receiving their diagnosis. If a parent decides to wait longer, it is generally recommended to tell children prior to starting middle school at the latest. Parents tend to stress about how they should go about telling their child. It's best to have a neurodiversity positive household and having inclusive conversations and books as early as possible. You can start this today! A good way to introduce this is by:

1. Everyone is different: Just like everyone looks different on the outside, everyone's brains are different too. We all have our own unique strengths and weaknesses- and this is a GOOD THING!
2. Invisible Disabilities: There are many disabilities we can see just by looking at a person. But there are many that we cannot see just by looking. Just because we can't see it, doesn't mean it's not there. You can name some (Autism, ADHD, chronic pain), and talk about what these are (brain differences) and what they are not (unintelligent, wrong, bad, etc).
3. Kindness and including others: Even though we are all different, we all have the same needs.

When it's time to tell your child about their diagnosis, hopefully they are familiar with the idea that everyone's brains are different and it likely won't be a big shock to them. You can tell your child with a book or video, use pictures, act out scenes, make a social story, or tell them in simple words. This does not have to be a one time conversation, and you can talk about it over a period of time. Here's an example script: "We have something we want to tell you. Remember how we talked about everyone's brains being different? Well, your brain is different, and the name for how your brain is different is Autism. You know how you get upset by sudden changes or loud sounds, and you like to flap your hands when you are excited? Those are things you do because you are Autistic. Being Autistic isn't bad or wrong, it's just different. It may mean you need support in areas that most people don't need support in, but that's okay. It's just different and you are perfect and we love you just the way you are."

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PARENT FEELINGS:

Learning that your child may need an Autism evaluation or is getting an Autism diagnosis can be really difficult for many parents and caregivers to hear. It may have caught you off guard or it may have been expected and still difficult to hear. MANY adults struggle to hear and respond to this information. This is often due to a lack of understanding of what Autism truly is but also many caregivers worry about their child's future with this diagnosis. It's important to note that adult reactions to this information are often emotionally charged and as humans, our emotions are not always rational. So if you denied, laughed, cried, yelled, felt relieved, felt guilty, or even felt numb- all of that is typical. Caregivers should know that however they initially react to this information is okay. Your feelings are valid. We do not choose our emotions, and they are nothing to be ashamed of. Parents should also know that their feelings about their child's diagnosis (or possible diagnosis) now are not equal to how they will feel about it in the future. Feelings change and it's common for things that are initially overwhelming to be more manageable or even positive emotions and experiences in the future. So take some time to feel your feelings, breathe, process, and talk to someone if you need to. Common questions parents ask are:

- DID I CAUSE THIS? WHAT COULD I HAVE DONE DIFFERENTLY?

  So many parents wonder what they did. "I let him have too much screen time," "I didn't talk to her or read her enough books," "I wasn't able to breastfeed them," "I didn't speak enough English," "I should have spaced out vaccines," etc. Autism is a neurological difference in a child's brain. While some of the things listed can certainly impact a child's development, they cannot cause Autism. You did not do anything wrong.

- DID BIRTH TRAUMA OR ACCIDENT CAUSE AUTISM?

  Many parents wonder if they did something during pregnancy, or if a traumatic birth event could have caused their child's Autism. At this point, we do not have a firm understanding of the exact cause. We know genetics plays a huge role, but not everyone with the Autism related genes will get an Autism diagnosis. It is likely a combination of genetic predisposition combined with environmental factors. It's possible that trauma or accident may have impacted a child, but is likely not the sole factor/cause for Autism.

- THIS IS NOT WHAT I EXPECTED FOR MY CHILD:

  It's common for parents to feel they need to mourn the life they thought their child would have when they are given a diagnosis. Parents should do what they need to do- without judgement- to process their emotions. If that means mourning the life you dreamed for your child, that is okay. Read the poem, "Welcome to Holland" and take the time to accept that life may be different than what you expected. However, an Autism diagnosis alone doesn't necessarily mean that your child cannot do all of the things you thought they might, AND we should always remember that our children control their own lives anyway, so our dreams are not always equal to our children's dreams regardless of if they are neurotypical or neurodivergent.

- WILL MY CHILD HAVE A NORMAL LIFE?

  Yes, autistic people can choose to go to college, get married, have a job, become a doctor or astronaut, have children, and all of the things. However, it is possible that they may choose to not do those things, and it's also possible that they have other diagnoses (such as intellectual disability, severe anxiety or depression, etc) that may impact them in significant ways that will impact many aspects of their life.

- WILL I NEED TO TAKE CARE OF THEM THEIR WHOLE LIFE?

  Many Autistic individuals are able to lead independent lives. Some need support throughout their lives, and the thought of this can be understandably be very overwhelming for parents. If you think your child may need continued support, speak with your evaluator about possible waitlists and supports that may be available in your area (such as respite care). It may also be helpful to find a professional who can assist you with future planning.

- AM I EXAGGERATING OR OVERREACTING TO THINK MY CHILD COULD BE AUTISTIC?

  Unfortunately, it's quite common for parents to wonder this and it is often due to well-meaning friends, family, and professionals telling parents "Don't worry" or sharing anecdotal information about their cousin's child who didn't speak until they were four and has a successful career. So many of the Autism characteristics are also seen (usually to a lesser degree) in typically developing children. This leads parents to wonder if they are over-reacting when they bring up concerns to their pediatrician or insist on getting an evaluation when others do not think it's necessary. This is not an over-reaction, and parents are correct to trust their gut. An evaluation is never a bad idea, and will give parents good information whether a child is given a diagnosis or not given a diagnosis.

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AUTISM FAQ:

- WHAT CAUSES AUTISM?

  At this time there is no singular answer. It is likely a mixture of genetics and environmental factors, with genetics being the current leading cause. Research shows that vaccines are not a cause.

- ARE SIBLINGS MORE LIKELY TO GET A DIAGNOSIS?

  Yes. Current research indicates siblings have an 18-31% of also getting a diagnosis, and in identical twins, a 36-95% chance of being diagnosed.

- WILL THEY OUTGROW IT?

  No. Autism is a lifelong brain difference. However, children diagnosed with Autism will change, progress, and improve in skills with time, just like any other child.

- IS THERE A CURE? CAN DIETS AND PROTOCOLS REVERSE AUTISM?

  No. There is not a cure and diets cannot reverse Autism because it is a neurological difference. It is possible diets and medication can improve medical symptoms associated in Autism (there is a link to gut-health) which may improve quality of life as well as one's ability to learn and progress.

- WHAT AGE CAN KIDS GET AN ACCURATE DIAGNOSIS?

  Current research indicates that Autism diagnoses given at 18 months of age are stable over time. However, some kids assessed at a young age do not get an initial Autism diagnosis, but get one at a later date as characteristics may become more clear or significant with age.

- HOW DOES AUTISM CHANGE OVER TIME?

  Many people think that Autism stays the same, but Autistic kids learn and grow just like everyone else. While they are commonly initially delayed, many Autistic children do learn to point, speak, make eye contact, engage in conversation, etc. They may also learn new and better ways to cope with areas of difficulty and/or sensory differences which makes their differences less observable.

- WHAT DO I DO IF MY CHILD HAS SIGNS BUT DOES NOT GET A DIAGNOSIS?

  Many times when children are young, it can be difficult for evaluators to pinpoint a diagnosis that best fits the child. It's okay to wait a few more years and get another evaluation at a later age. In the meantime, children can participate in needed therapies without a diagnosis.

- WHAT IF MY CHILD IS ONLY SHOWING SIGNS AT SCHOOL?

  Autism is not something that impacts kids only in one location, it would be present in all settings. It's possible that parents do not recognize Autistic characteristics because they may be subtle. Additionally, school expectations are typically much more than home expectations, so it is relatively common for a child to have more difficulty at school due to this. Likewise, some kids do well at school because of classroom routines and structure and then struggle at home, often either due to lack of structure or exhaustion from keeping it together all day at school.

- WHAT DOES A DIAGNOSIS CHANGE? WILL A DIAGNOSIS CHANGE THERAPY?

  In some locations, a medical Autism diagnosis may change what your insurance company will cover in therapy. However, ideally therapy and interventions should be given based off of a child's individual needs and not a diagnosis alone.

- WHY SHOULD I GET A DIAGNOSIS NOW IF IT DOESN'T CHANGE MUCH?

  Diagnosis is about more than getting services. A diagnosis can help family and teachers better understand a child's needs and actions, as well as have some clues into how they child may best learn. More importantly, having a diagnosis can help an individual better understand themself and know that nothing is wrong with them, their brain is simply wired differently.

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- WHY HAVEN'T MY PEDIATRICIAN OR PREVIOUS THERAPISTS MENTIONED AUTSIM?

  Autism is a complex condition and many professionals only know the stereotypes of Autism. This can lead kids who are social or make eye contact to go undiagnosed or misdiagnosed by generalists.

- MY CHILD STRUGGLES IN NEW SITUATIONS, HOW CAN I PREPARE THEM FOR THE EVALUATION?

  Speak to your evaluator about your concerns prior to bringing your child in for assessment. They may be able to send pictures of the assessment room, or let you see the space prior to the actual evaluation. This may also let the evaluator know that your child will need time to warm up and get comfortable prior to beginning the assessment. Evaluators should also recognize that children will not show all of their skills within the assessment - which is why caregiver report is important.

- HOW DO I GET AN EVALUATION?

  There are many ways to get an evaluation. If you are in the U.S., call early intervention or your local school district and ask about evaluations. You can also talk to your pediatrician about a referral.

- I AM READY TO GET OUR CHILD EVALUATED, BUT MY PARTNER IS STRUGGLING, WHAT SHOULD WE DO?

  This is a very common situation, and one that can get tricky. It may be a good idea for partners to schedule a time to sit down and go over each of their reasons for their opinions on evaluations. Families can schedule an appointment with their pediatrician or other specialist to talk about positives and negatives about getting an assessment. Many parents just need time to process and accept that their child may be different. It may be a good compromise to support with intervention before getting a formal assessment or diagnosis.

- WILL MY CHILD BE PUT IN A SEPARATE CLASS OR SCHOOL IF THEY GET A DIAGNOSIS?

  An Autism diagnosis alone should not decide how or where a child is educated. Some children may have high support needs while others' needs can be met in a general education classroom. Parents are encouraged to discuss this possibility with their child's education team.

- WHAT IS MY FIRST STEP AFTER DIAGNOSIS?

  This depends on the child's needs as well as each individual parent. Some parents will need time to process a new diagnosis while others are ready to jump in to learn more about Autism and set up supports for their child. Parents are encouraged to do whatever they feel is best for their family. Parents may benefit from joining support groups or talking to a therapist if they are struggling.

- IF IT IS AUTISM, HOW CAN I FIND OUT WHAT LEVEL MY CHILD IS?

  When medical professionals assess for Autism using the DSM-5, they will give a level as part of the diagnosis. These levels do not necessarily remain consistent over time or across settings.

- IF IT'S NOT AUTISM, WHAT COULD IT BE?

  A child could be neurotypical, have a language delay, or be neurodivergent due to a variety of reasons most often but not limited to ADHD, Gifted and Talented, Anxiety/Depression, mental health disorders, OCD, developmental delay, intellectual disability, or have prenatal drug exposure.

- MY CULTURE DOES NOT VIEW AUTISM IN A POSITIVE LIGHT, WHAT SHOULD I DO?

  What you do is completely up to you. Many parents decide to move forward with assessment and support (if needed) for their child and many decide to wait. It's important for parents to have all of the information available and then decide what is best for their family- judgement free.

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- DO I HAVE TO TELL FRIENDS AND FAMILY ABOUT MY CHILD'S DIAGNOSIS?

  Only if you want to. Sharing about a child's diagnosis is completely up to the parents/guardians. You can choose to keep to yourself, share with only close family and friends, or tell everyone.

- ARE THERE ANY FAMOUS PEOPLE THAT ARE AUTISTIC?

  Yes! There are many confirmed and suspected famous Autistic people. Confirmed Autistic celebrities include: Anthony Hopkins, Dan Aykroyd, Darryl Hannah, Courtney Love, Elon Musk, and many more.

- SHOULD I STOP MY CHILD FROM FLAPPING THEIR HANDS OR STIMMING?

  No. Stimming has been found to help autistic people self regulate. Caregivers and teachers should avoid blocking or stopping stimming unless it is harming the child or another person. If a stim is harmful, a replacement stim should be provided. An Occupational Therapist (OT) may be helpful in this area.

- SHOULD I TRY TO MAKE MY CHILD MAKE EYE CONTACT?

  No. Many Autistic individuals describe eye contact as painful, or report it is difficult to focus on conversation or schooling if they are making eye contact. Also, eye contact is very nuanced, so if you do not use it naturally, it can be very difficult to recognize all of the unwritten rules, and this often results in prolonged eye contact and staring, and having an opposite impact than intended.

- HOW CAN I SUPPORT MY CHILD'S SENSORY NEEDS?

  Working with an Occupational Therapist (OT) may be helpful in supporting children's sensory needs. Children may benefit from a sensory diet to address their individual needs. Children should be given access to sensory based activities as often as they need to help keep them regulated. One size does not fit all, so it's important to work with a specialist to determine a child's needs.

- DOES MY CHILD NEED A RE-EVALUATION LATER IF THEY WERE DIAGNOSED AFTER THE FIRST ONE?

  This is up to the parent. Generally, a re-evaluation is not recommended unless someone questions the original diagnosis. If everyone agrees Autism is the best diagnosis, a more informal update of progress may be better suited rather than completing updated formal Autism assessment. If an Autism diagnosis is questioned, then a re-evaluation should be completed.

- WILL MY CHILD MAKE FRIENDS?

  This is (and should be!) completely up to your child. Many parents stress over this because they feel friendships are important to them. But sometimes friendships aren't important to kids, or they prefer to interact with adults, and that's okay. If having friends is important to your child, they will likely make friends. Research suggests that Neurodivergent individuals tend to get along with other Neurodivergent individuals, so if your child is struggling, it may be helpful to find children similar to them and support them as needed with developing friendships.

- HOW LONG WILL MY CHILD NEED INTERVENTION?

  The duration of intervention varies from child to child. Some children do not need direct intervention, some need it throughout their primary and/or secondary school years, and others need long-term support. Parents should know that support such as speech or occupational therapy are generally not a "quick fix" and takes time. Many children may need to work on prerequisite skills before observable progress is made with skills like speaking and writing.

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- WILL MY CHILD EVER TALK?

  There is no way to predict your child's future. While the majority of children do go on to speak, some children do not. Positive indicators of speech include babbling, echolalia, and scripting. However, for Autistic children with delayed language, an alternative or augmentative communication (AAC) system should be considered early. AAC can be low tech with sign language or pictures to help children communicate or high tech such as a full communication app on an iPad.

- MY CHILD DOESN'T SPEAK, CAN THEY UNDERSTAND ME?

  A speech and language evaluation can tell you how much your child is able to understand. However, not all children will perform to their actual abilities on assessments for a variety of reasons. Due to this, it is recommended that parents and professionals always assume competence. Assume the child can understand everything you say, even if they do not respond in real time.

- IF I GIVE MY CHILD ASSISTIVE TECHNOLOGY, WILL IT STOP THEM FROM SPEAKING?

  No. This is a myth. Use of pictures, devices, and sign language to facilitate communication early on has been found to support the use of verbal speech. Giving a child a way to communicate in a manner accessible to them is incredibly important and supports their continued language growth while decreasing communication related tantrums.

- MY CHILD LOST WORDS IN A REGRESSION, WILL THEY GET THEM BACK?

  Unfortunately, there is not a way to predict if a child will be able to regain skills lost in a regression. Children do frequently gain back words after a period of several months, but this is not always the case. If a child loses words, it may be a good time to consider Augmentative and Alternative Communication (AAC).

- WHAT PERCENTAGE OF CHILDREN SPEAK AND WHAT AGE DOES IT TYPICALLY HAPPEN?

  At this time, we don't really know. Previous research has found that 60% of autistic children are able to speak, but it is likely that this research did not include a range of individuals on the spectrum and it is more likely that this number is significantly higher. Many autistic children do not speak until 3-4 years of age, and others do not speak until 7 or later. Parents of nonspeaking children are encouraged to look into AAC options to give their child the power of communication while they wait for speech.

- WHAT CAN I DO TO SUPPORT MY CHILD'S COMMUNICATION?

  Picture supports and AAC can make a huge difference for a struggling communicator. Caregivers can model language as they go about everyday routines by saying the words they think their child may want to say, or by commenting on their or their child's actions. Extend on what your child says by adding one to two words or concepts; if a child says "cat" the adult can say "big cat." Adults can give lead in or fill in the blank statements to see if a child can complete a phrase, and be sure to allow a child time to process and respond. Caregivers can repeat what the child says, and respond to communication sounds or attempts to validate the child's communication. Adults should avoid asking children to label items repeatedly by asking, "What is this?" Or otherwise overload children with too many questions (try to make 3-4 statements for every question). Caregivers should also avoid saying "say" ("say dog") or pressure children into speaking. If your child has communication differences, it's important to work with a Speech Language Pathologist for more specific support and recommendations.

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ADDITIONAL RESOURCES:

- WEBSITES:
  - www.autisticadvocacy.org - The Autistic Self Advocacy Network is led by Autistic adults and has many free and available for purchase resources for parents.
  - www.autismnavigator.com - Autism Navigator has a free ASD video glossary of side by side videos of typically developing children and children diagnosed with Autism doing similar activities. This can help parents recognize the early signs of Autism, and how that may look in real life.
  - www.neuroclastic.com - Neuroclastic is a website run by a collective of Autistic adults and regularly posts articles and resources made by the Autistic population.
- BOOKS:
  - Uniquely Human: A Different Way of Seeing Autism by Barry Prizant
  - Sincerely, Your Autistic Child by AWNN
  - Loud Hands: Autistic People Speaking by Julia Bascom
  - Autism: An Inside-Out Approach by Donna Williams
  - NeuroTribes: The Legacy of Autism and the Future of Neurodiversity by Steve Silberman
  - The Explosive Child: A New Approach for Understanding and Parenting Easily Frustrated, Chronically Inflexible Children by Ross W. Greene
- SOCIAL MEDIA:

Autistic Accounts:
- @The.Autisticats
- @TheAutisticLife
- @Neurodivergent_Lou
- @Autism_sketches
- @TheAutismCafe
- @Fidgets.and.Fries
- @JustKeepStimming

Professional Accounts:
- @MrsSpeechieP
- @Play_Spark
- @LearnPlayThrive
- @TheExpertAlly
- @JessieGinsburg.SLP
- @MeaningfulSpeech
- @RachelMadelSLP

Parent Accounts:
- @CariEbertSeminars
- @aFriendforLillyBug
- @Graciellablooms
- @Ot_mama_of_twins
- @LeahBehrens
- @NicoleGottesmann
- @AutismSuperMoms

- VIDEOS:
  - Welcome to the Autistic Community: https://youtu.be/XnuGPJ7UdpU
  - Amazing Things Happen: https://youtu.be/RbwRrVw-CRo
- PODCASTS:
  - Uniquely Human
  - Learn Play Thrive
  - Laura Mize

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KAITLYNN HAMMOND, 26

As a child I struggled socially and verbally. I was difficult to understand and was told I sounded like I was speaking with a mouth full of rocks. I was almost held back in kindergarten because I had a hard time making friends. I always preferred the company of animals and books, and I couldn't stand socks! I wasn't diagnosed with Autism until I was 25 (after my son's diagnosis), so I was called quirky, anxious, and "anti-social" growing up. Once I hit my teens, that's when my struggles became more apparent to me. I struggled with depression, disordered eating, terrible anxiety, and just an overall sense of not fitting in no matter how hard I tried. I used to bite my nails until they became infected and dance without music (both stims). People thought I was weird because I collected stuffed animals. I also have special interest of Harry Potter, animals, and psychology. In 2020, my oldest son was diagnosed as Autistic at 23 months old. He stopped talking/babbling and had meltdowns when around other kids. He had a set routine and was very anxious. We were told he was a boy and would grow out of it until he was 18 months old and we found a pediatrician that recognized our concerns. He is non-speaking but just started using AAC, and is honestly the sweetest, funniest, most cuddly little boy ever! He loves to swing, line up hot wheels, and hum along to Frozen songs. We had our daughter evaluated at 19 months after she had a major speech regression (and were again told it was nothing to worry about). She had little stims of flicking her fingers repeatedly, only saying "mom" all day, flicking her toes, and spinning. She would engage in repetitive play but is so quick to learn new things. She is overly social and will hug strangers and want to be their friend, and her eye contact was intense. I'm currently a stay at home mom to three under three, a small business owner, and a full time student. Our house is basically a sensory gym in order to get everyone's needs met. My biggest advice for parents new to Autism is to learn from the Actually Autistic community. We are here to help and educate. Also, when you are starting the journey to understand meltdowns and sensory needs, keep a journal of everything! Meltdowns never happen "for no reason"- and a journal will help understand any triggers and can help create a calm environment. You'll have hard days, but you've got this! Self-care as a parent is a must, even if it's just noise reduction ear plugs to help through the yelling stims. Just... Be open to learn. People who live it and know what it feels like on the inside are often the best ones to shed light on how to help. There's no need to look for a cure, we can be extremely successful in our own ways. We just need acceptance.

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EZRA, 18

Looking back, I was a fairly "typical" Autistic kid. My earliest teachers called me "shy" and would comment that I spent all of my playtime lining up blocks in specific color patterns. I was also the toddler that threw "tantrums" at loud parties and whenever there was a routine change. Because Autism was a "boy thing," I was instead diagnosed with childhood-onset Anxiety. For one reason or another, my Autistic traits were ignored or misattributed until middle school, where the demands of public school began to exceed my abilities. My parents ended up pulling me out of school for my own mental health, and I was finally diagnosed with Autism when I was 12. Most of my needs were sensory-based, as I was considered "twice exceptional" (gifted and disabled). I was given access to sensory breaks and was allowed to leave the classroom as needed to calm down. I briefly attended Occupational Therapy to help with fine motor skills like shoelace tying and handwriting. My mom had to fight to keep me out of interventions that were explicitly described as being designed to help me seem more neurotypical. Without my parents to protect me and encourage me to grow and learn at my own pace, I would not be the person I am now. Today I am a university student and a member of a prestigious national academic honor society. My special interests in contemporary history and world cultures inspired me to pursue a degree in Global Security with a focus in Counterterrorism. I still have accommodations for my sensory needs, and am starting on an AAC journey to help me communicate when I'm overloaded or tired. I have a lovely partner whom I adore, and I still think my mom is a superhero. My advice to parents is to never be afraid to advocate for your child. You are your child's first line of defense against a world that wants them to break themselves down and force themselves into a box that doesn't fit them. Boxes are for toys and shoes, not people!

AJ, @SENSORYHUMAN, 16

I was diagnosed with Autism at the age of 15. As a child, I had sensory and social differences, but these went unrecognized. I was very much a "gifted kid," and that was really the only thing that was recognized. I was often viewed as "whiny" or a "complainer" and often complained about outdoor activities. In reality, I was just very overwhelmed and I didn't know how to communicate that other than by complaining. I wish my parents had been able to look more into the reasons for why I did the things I did, and feel that support would have helped me. I would want parents of a child new to an Autism diagnosis to encourage your child's autonomy the same way you would encourage them without a diagnosis. It's important for people to communicate however is comfortable to them, so AAC is always a good idea. And most of all, love every part of your child. Autistic kids are AMAZING and your child is so special!

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SAMANTHA ROWNTREE, CPSP, @THE_AUSSIESPEECHIE, 24

As I grew up, I always knew I was different. My brother was diagnosed with Autism when he was two but I was not diagnosed until adulthood. Growing up, I didn't 'fit in' at school- I was way more passionate, but it was viewed negatively by the other kids. Now that I'm an adult and diagnosed, I look back and can understand why. I can accept who I am and why I'm different from others, and I know it's okay! My self esteem has risen so much. As an adult, I am a Speech Therapist and I have seen first hand how much validation can help parents feel more confident in supporting their child. Parents, I know you are scared right now, and that is so valid. It is scary. Knowing your child is different and may not have the life you envisioned for them. But please remember you child is still special, wonderful, and amazing. Celebrate the small things. Make sure they know they're loved and you are proud of them. Make sure they know it's okay to be different, because hearing that from your parents and loved ones is the most freeing feeling you can ever have.

REBECCA SALISBURY, 25

I was recently diagnosed a few months ago at 25 years of age. My childhood seemed pretty typical, and my parents did not have any concerns. A family friend, who was a speech language pathologist, mentioned a couple of times that I could be Autistic, but my parents didn't think anything of it. I did not have language delays, but was much quieter at school than at home. I found it easier to interact with younger children, but had friends my age. At age 17, I started seeing a psychologist for depression and social anxiety, and have seen mental health professionals since then. I have suspected for a few years that I was Autistic, and since being diagnosed, a lot of the things I struggled with make more sense and I have a better understanding of myself. I've always loved children and work in a childcare center, as children and childcare is my main special interest. I've always had sensory differences, especially sensory overload, and now know to take a few minutes by myself to cope rather than becoming overwhelmed. I understand why I enjoy repetitive tasks at work, like filing, and that doing these tasks can help me stay calm when things are tricky at work. I encourage parents to get their children evaluated, even if they are managing okay, because knowing how their brain works can be so helpful. I also think parents should teach kids how to advocate for themselves, by doing things like modeling how to ask for a sensory break. Expose your child to other neurodivergent children and adults when possible. Acknowledge that it's difficult to be Autistic, but don't talk about Autism like it's a bad thing, problem, or secret.

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RENÉE, 35

My brother was diagnosed with Asperger's Syndrome (now Autism) when he was 12. Growing up, Autism was seen as a problem. There was limited support, and no one was discussing it as a strength or asset. My brother was expected to fit in, and I feel pretty terrible about the lack of understanding we had. I had no idea that Autism presented differently in girls. I always felt on the outside of things, but I never considered the areas I struggled or my health issues to be related. My doctor dismissed many of my complaints as psychosomatic, and I was pretty hard on myself. I now recognize periods of intense exhaustion and overwhelm as Autistic burnout. My special interest was reading, and I achieved good grades, so my parents just assumed I was easily distracted, introverted, and highly sensitive. My closest friend had a son 6 weeks older than my daughter. She mentioned she was getting her son evaluated because he was not meeting milestones, and at that point I realized my daughter wasn't meeting speech milestones. Although her pediatrician thought me overly cautious, he agreed to a referral. She began therapy with a generalist, eventually moving on to a speech therapist and occupational therapist. No one ever mentioned Autism. When she was evaluated by the school district for services at age 3, the Autism eligibility they gave her felt out of left field. In hindsight, there were so many indicators, but I knew so little about Autism and girls. A few months later, she received her clinical diagnosis. I was lucky to be following a couple of SLP accounts on Instagram, which introduced me to Autistic adults. I had a lot of unlearning to do and some internalized ableism. As I learned more about Autism, I saw that the things that I had struggled with as a child and as an adult were connected- and they were Autism. My clinical diagnosis came 6 months after my daughter's. I was very fortunate that my daughter's first speech therapist had Autistic children. She told me that my daughter was exactly the same child she had always been and whom I had always loved. The only thing that had changed was that I now had an understanding of her that would enable to me to support her better. Listening to Autistic adults helped me recognize Autistic strengths, advocate for my daughter more actively, and reframe my own experiences.

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Teacher Letters:

THE FOLLOWING PAGES WERE MADE FOR YOU TO PRINT AND GIVE TO TEACHERS, THERAPISTS, OR OTHER INDIVIDUALS WHO WORK WITH YOUR CHILD/STUDENTS. THE FIRST LETTER IS FOR TEACHERS FROM THERAPISTS, AND THE SECOND LETTER IS FOR TEACHERS/THERAPISTS FROM PARENTS. THE THIRD LETTER CAN BE USED BY BOTH PARENTS AND PROFESSIONALS. I PURPOSELY LEFT THE SIGNATURE BLANK FOR YOU TO SIGN, SO DON'T FORGET TO SIGN YOUR NAME AT THE BOTTOM!

YOU MAY PRINT AND USE THESE LETTERS AN UNLIMITED AMOUNT OF TIMES FOR YOUR CHILD/STUDENTS, BUT PLEASE DO NOT SHARE WITH OTHER PARENTS/PROFESSIONALS. IF OTHERS WOULD LIKE A COPY, PLEASE DIRECT THEM TO MY WEBSITE TO PURCHASE, WWW.MRSSPEECHIEP.COM

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Dear Teacher,

First, I just want to thank you for everything you do for your students every day. I know teachers do not hear this enough, but you are so appreciated! You are receiving this letter because I want to let you know that my child is on the Autism spectrum. You have probably had students with this diagnosis before, and just like any child you have worked with, you likely have had both positive and negative experiences with these children. I would really love if my child could start fresh from any preconceived notions you may have about any past experiences so that you can get to know them as an individual.

I wanted to share a few things with you about Autism. First, many people think Autism is a "bad" or "negative" thing - and while my child has their struggles and support needs, I just want to share that our family celebrates Neurodiversity and do not view Autism as bad. My child is not "broken" and does not need to be "fixed", but they do need love, support, and acceptance for who they are - just like any child.

Things I want you to know about my child and children on the Autism spectrum:

1. Please be patient and kind with my child and love them for who they are - strengths, flaws, and all. Please don't assume my child can or cannot do things just because of their diagnosis or even past experiences with my child.
2. Many children on the Autism Spectrum learn differently. They may not look at you and may fidget or look around the room in a way that makes them look like they are not listening even when they really are. It may be helpful to talk to kids about how they can best focus and learn, even if it's not the way most teachers expect, and please accept this in your class. Instead of asking a child, "Do you understand?", please have them demonstrate their understanding (by doing a task or paraphrasing).
3. Many children have sensory needs that need to be met in order to access their learning. This may mean they need space to move about such as an opportunity to jump/spin/move, or they may need something to fidget with to help them focus on their tasks. If a child is not regulated or getting their sensory needs met, they will not be able to listen, focus, or learn. Just like you wouldn't listen and learn in a crisis event, my child will not either. The only difference is that small things that seem insignificant to you may feel like a crisis to a child and put them in a fight or flight physiological response to stress.
4. Please do not assume my child is purposefully acting out. While I realize that happens sometimes, very often children are overwhelmed with anxiety and do better with support and understanding over punishment (especially when they are in the moment or on the brink of or in the middle of a meltdown).
5. It will likely be helpful if you avoid abstract words or phrases when talking to my child. They might need additional explanation or direct teaching to understand what these mean when you use them.
6. Many children benefit from clear expectations. They may need taped off spaces for where to keep their body or a safe place to pace and move about. They may need a visual schedule that is frequently referenced throughout the day, and they may need to be warned with as much notice as possible about changes in routine.
7. Please focus on what my child can do and nurture those things. If you can incorporate my child's interests into learning, they will be much more excited and motivated to participate and learn. This may be allowing them to incorporate it into their writing or reading, or adding it into math problems.

Thank you so much for reading this far and keeping these considerations in mind throughout the year. We are so excited to have you as a teacher and look forward to a great year!

Sincerely,

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Dear Teacher,

Student:

Here are some specific things about our student that may support you in your ability to get to know them and support their needs. Please let me know if I can clarify any of these or if there is anything I can do to support you or our student.

Communication Strengths:

Communication Needed Supports:

Special Interests:

Sensory Needs/Regulation Support:

Other:

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RELEVANT RESEARCH ARTICLES:

• ARTICLES ABOUT NEURODIVERSITY:

DAVIS, R. & CROMPTON, C. J. (2021). WHAT DO NEW FINDINGS ABOUT SOCIAL INTERACTION IN AUTISTIC ADULTS MEAN FOR NEURODEVELOPMENTAL RESEARCH? PERSPECTIVES ON PSYCHOLOGICAL SCIENCE. HTTPS://DOI.ORG/10.1177/1745691610958010

LAURENT, A. C. & FEDE, J. (2021). LEVELING UP REGULATORY SUPPORT THROUGH COMMUNITY COLLABORATION. PERSPECTIVES OF THE ASHA SPECIAL INTEREST GROUPS. HTTPS://DOI.ORG/10.1044/2020_PERSP-20-00197

MITCHELL, P., SHEPPARD, E., & CASSIDY, S. (2021). AUTISM AND THE DOUBLE EMPATHY PROBLEM: IMPLICATIONS FOR DEVELOPMENT AND MENTAL HEALTH. BRITISH JOURNAL OF DEVELOPMENTAL PSYCHOLOGY. HTTPS://DOI.ORG./10.1111/BJDP.12350

• DELIVERING DIAGNOSIS OR REFERRALS:

PATTISON E., URE, A., MITTIGA, S.R., WILLIAMS, K., & FREEMAN, N.C. (2021). THE FEEDBACK SESSION OF AN AUTISM ASSESSMENT: A SCOPING REVIEW OF CLINICAL PRACTICE GUIDELINE RECOMMENDATIONS. JOURNAL OF AUTISM AND DEVELOPMENTAL DISORDERS. HTTPS://DOI.ORG/10.1007/S10803-021-05067-9

GOODWIN, A., MATTHEWS, N. L., & SMITH, C. J. (2018). PARENT-REPORTED EARLY SYMPTOMS OF AUTISM SPECTRUM DISORDER IN CHILDREN WITHOUT INTELLECTUAL DISABILITY WHO WERE DIAGNOSED AT SCHOOL AGE. AUTISM. ADVANCE ONLINE PUBLICATION. DOI: 10.1177/1362361318777243

• AAC:

WHITE, E.N., AYRES, K.M., SNYDER, S.K., CAGLIANI, R.R., & LEDFORD, J.R. (2021). AUGMENTATIVE AND ALTERNATIVE COMMUNICATION AND SPEECH PRODUCTION FOR INDIVIDUALS WITH ASD: A SYSTEMATIC REVIEW. JOURNAL OF AUTISM AND DEVELOPMENTAL DISORDERS. HTTPS://DOI.ORG/10.1007/S10803-021-04868-2

• CULTURALLY RELEVANT INFORMATION:

DABABNAH, S., KIM, I., & SHAIA, W. (2021). I AM SO FEARFUL FOR HIM: A MIXED-METHODS EXPLORATION OF STRESS AMONG CAREGIVERS OF BLACK CHILDREN WITH AUTISM. INTERNATIONAL JOURNAL OF DEVELOPMENTAL DISABILITIES. HTTPS://DOI.ORG/10.1080/20473869.2020.1870418

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